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Refused-knowledge during the COVID-19 Pandemic: Mobilising Experiential Expertise for Care and Well-being

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ABSTRACT



Since the early period of the COVID-19 pandemic concerned groups of people have produced knowledge refused by institutional science of how to manage public health and individual well-being in everyday pandemic life. Research in science and technology studies seeks to understand the social and cultural conditions under which contestation over scientific knowledge claims occurs. In the Italian case, 'refused' knowledge claims emerging outside institutionalised science play a performative role in questioning the current models for managing individual and public health. Such refused claims ascribe novel meanings to the COVID-19 pandemic and orient the ways in which people manage their own health and well-being during their everyday life. Two interrelated dimensions are at stake in the production and enactment of refused knowledge: (1) how experiential expertise is mobilised to reframe one's body in a process of self-care, thus validating a corpus of refused knowledge through personal experience, and (2) how narratives demarcate between a body of refused knowledge and the prevalent biomedical paradigms as a way of gaining experiential epistemic autonomy.

KEYWORDS

COVID-19 pandemic; thought style; thought collective; refused knowledge; web ethnography; Italy

Introduction

In the last decade, both in the public sphere and in academic circles, public debate on trust in science has expanded due to the media visibility gained by knowledge that conflict with scientific expertise (Harambam, 2020a, 2020b; Prasad, 2021). According to van Zoonen (2012) and Harambam and Aupers (2015, 2017), the heart of this conflict lies in the claim that forms of knowledge

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other than institutionalised scientific knowledge can be usefully mobilised to address public issues.

More recent research on COVID-19 illustrates how concerned groups of people, often relying on digital media, have questioned both the information released by scientific institutions and the policies implemented by governments to stem the pandemic (see Desta and Mulgeta, 2020; Lasco, 2020; Prasad, 2021; Bory *et al.*, 2022a, 2022b). In doing so, these groups have produced knowledge claims refused by institutional science of how to manage public health and individual well-being during the pandemic. The institutionalised scientific and medical communities engaged in producing clinically actionable knowledge and therapeutic options, policies, and protocols to combat COVID-19 during the first months of the pandemic in Europe (late January 2020–late July 2020) were primarily based on lifestyle and behavioural changes. This led to an ensemble of prescribed norms (e.g. physical distancing measures, mandatory use of personal safety protection devices) that were rejected by concerned communities of people who were distrustful of institutionalised science.

In addressing public resistance toward scientific knowledge claims and advice, some institutional experts and segments of the scientific community have argued that traditional epistemic institutions (e.g. health agencies and medical associations) and gatekeepers of knowledge claims (e.g. journalists and public intellectual elites) have lost their monopoly on defining the content of public communication about health and illness issues (Larson, 2018; Armstrong and Naylor, 2019; Gustafson and Rice, 2020). In contrast, a range of alternative public health and medical knowledge claims have acquired an unwarranted relevance (see Desta and Mulgeta, 2020).

With no intention to belittle such public concerns about the need to stop the circulation of fraudulent or inaccurate claims about public health, it is relevant to say that the questioning of accredited scientific knowledge is not merely centred on the COVID-19 pandemic itself. Therefore, questioning scientific authority cannot be framed as a contingent lay response to the institutional governance of this particular global outbreak. Rather, it is rooted in long-term social transformations concerning: (1) growing (mis)trust in technical expertise due to the belief that scientific progress may have unintended consequences that science is increasingly unable to manage (Oreskes, 2019); and (2) a growing consensus around the usefulness of alternative models of caring and healing in the last decades among both ordinary citizens and communities of healthcare professionals (Brosnan *et al.*, 2018; Vuolanto *et al.*, 2020).

Recognising the centrality of these social dynamics in reconfiguring the nexus between science, technical expertise, and society, we examine contemporary discourses and claims emerging outside institutionalised science against the prevalent biomedical sciences by viewing them as performative interventions to question the current models of managing individual and public health. We investigate how such performative interventions may

ascribe novel meanings to the COVID-19 pandemic and how they orient the ways in which people can manage their own health and well-being during the pandemic.

Even though we are aware of the ethical and social concerns about the spread of health- and illness-based accounts rejected by the institutional scientific community, we assume an analytical rather than normative position. This allows us to propose an interpretative framework for understanding the content of such refused knowledge claims without passing judgement on their ethical value or assessing whether a given belief is ‘rational’ or ‘true’ according to the prevalent scientific criteria. As Goldenberg (2016) and Harambam (2020b) suggest, although since the 1990s social studies of science have questioned the normative models that portray the public as inherently ignorant and scientifically illiterate, there is still a need to carefully consider and understand the social and cultural conditions under which contestation over institutionalised scientific claims occurs. Hence, we aim to problematise the normative approach to addressing mistrust in biomedicine by asking the following research questions: What kinds of refused knowledge of care and well-being have been developed and shared in the context of the pandemic? In what ways did groups of concerned people develop strategies to enact such refused knowledge in everyday life during the pandemic?

It is worth noting that refused knowledge making practices have found fertile ground in the proliferation of digital spaces where actors question prevalent scientific explanations and share what they think about public issues that are subject to scientific scrutiny and intervention. Increasingly, these online settings leave digital traces that can be used as sources of data for studying those communities that rely on a body of refused knowledge: i.e. knowledge that is not fully compatible – if not entirely incompatible – with prevailing and institutionalised scientific and biomedical paradigms.

To analyse the content of refused knowledge mobilised in online settings, we employ the notions of ‘thought style’ and ‘thought collective’ developed by Fleck (1935). These concepts allowed us to analyse the knowledge-making processes and the related practices that communities of concerned people adopt to care for their bodies and minds to ensure a state of well-being and endure the pandemic. With this analytical focus, our study reveals the kinds of refused knowledge of care and well-being that are developed and disseminated online in the context of the pandemic, and the way in which this refused knowledge is rendered actionable in everyday life by concerned communities of people. In doing so, our study considers refused knowledge in relation to the current dominant scientific paradigm and the way in which people developing such knowledge make their biological bodies both the objects and the subjects of knowledge-making processes. Thus, our study sheds light on refused knowledge actionability strategies to identify the fundamental processes shaping refused styles of thought about SARS-CoV-2.

Analytical Perspective: Framing 'Anti-science' Practice and Experiential Expertise as a Refused Style of Thought

Popular suspicion against diverse scientific institutions and public health agencies has been framed by social scientists as a 'dangerous' attitude mainly related to practices of shaping, spreading and lending credibility to claims that have no scientific foundation (Gentilcore, 2006; Cattaneo and Corbellini, 2014; Cloatre, 2019; Lavorgna and Di Ronco, 2019). Furthermore, the digitalisation of social interaction and everyday life is often considered the main driver of the uncontrolled propagation of unreliable and inaccurate information, thus boosting mistrust in scientific knowledge and advice (Del Vicario *et al.*, 2016; Hale *et al.*, 2018; West and Bergstrom, 2021). In this view, cultural perspectives and discourses questioning the authority and trustworthiness of public health institutes, universities and other research and teaching organisations are strongly stigmatised in the public sphere and by members of the scientific community (Trethewey, 2020; for a critical examination of this point, see Prasad, 2021).

This perspective has been recently fuelled by several commentators and scholars studying contemporary anti-science attitudes, according to which we are in the midst of a 'post-truth' or 'post-factual' era dominated by fake news-making processes (Ball, 2017; d'Ancona, 2017; Davis, 2017; Fuller, 2018). McIntyre argues (2018, pp. 9–10) that these processes lead to an 'eclipse of truth', which challenges 'the existence of reality itself', where factual evidence are becoming increasingly irrelevant to public opinion and decision-making processes. Albeit with varying epistemological and conceptual nuances, the post-truth perspective is relevant to problematising the current notions of how scientific evidence can be mobilised in policy-making and in the public sphere at large. More generally, it helps recognising the extent to which public discussions about scientific facts and the reliability of scientific institutions are rooted in judgements of worthiness and can spark complex debates about the social meaning of 'truth' (Farkas and Schou, 2018; Pellizzoni, 2019).

At the same time, as Harambam (2020a) showed in the case of conspiracy theories, labelling an individual 'faker' and a phenomenon 'anti-scientific' is an analytical strategy that distinguishes different forms of knowledge by creating demarcation criteria for institutional scientific rationality. Thus, following Harambam (2020b) the increasingly broad appeal of labels such as 'post-factual society', 'post-truth' and 'fake news' seems to reinforce a normative approach that favours a kind of explanatory politics primarily aimed at expelling certain beliefs or individuals from the legitimate public and political debate, rather than explaining the social and cultural drivers of the resistance to established scientific facts. In a study that critically examined the current research trends related to post-truth, Lynch (2020) made the following remark:

The [...] contrast between ‘objective facts’ and ‘appeals to emotion and personal belief’ does not quite capture the challenge to science in the current era. Instead of an outright rejection of science and objectivity, what is involved is an effort to produce adversarial claims to objectivity and institutional support for those claims (Lynch 2020, p. 50).

By engaging in a dialogue with Lynch’s stance, we argue that contemporary practices of contesting science, and specifically the biomedical and life sciences, cannot be considered episodic or mainly triggered by digital media, nor can they be dismissed as an old form of scientific illiteracy or irrationality under a new guise or as the product of a deviant mindset existing on the margins of political and social life.

Assuming this analytical positionality, we explored the shaping of claims that are partially or completely refused by biomedical authorities and examined how such claims and experiential expertise are co-produced by concerned communities and then enacted in everyday life. Such communities negotiate and resist the prevalent biomedical discourse and expertise and produce knowledge that presents alternative meanings and options for addressing health and well-being.

To analyse refused knowledge and its enactment by communities of concerned people, we primarily relied on Fleck’s (1935) notion of ‘style of thought’ and its theoretical legacy in the field of the social studies of science and medicine (Löwy, 1990, 2004; Hacking, 1992; Wahlberg and Rose, 2015). Fleck proposed this concept to explore the ways of sharing knowledge between different communities of thought (e.g. physicians, life scientists and patients) to stabilise medical innovations, the relevance of physicians’ specialisation patterns to the production of medical knowledge, and the influence of popular experiential knowledge on experts’ definitions of nosological classes. According to Fleck, a style of thought is a particular way of knowing and practising because it concerns the shaping of claims and the mobilisation of material resources and technical equipment in a manner that is unique and appropriate to this way of knowing observable entities and phenomena (e.g. biological or physical). Claims and concepts – and the relations between them – can be systematised and codified in an intelligible grid that can orient argumentative practices and explanations of certain observable processes. According to Fleck, a ‘style of thought’ implies disciplinary or sub-disciplinary membership in a ‘thought community’ in which practices of managing power distribution, status and internal reputation are at stake.

In assuming this theoretical position, two interrelated dimensions are crucial for this study. The first concerns the patterns of learning and practising the style of thought within communities relying on a body of refused knowledge. The second concerns the degree of incommensurability between diverse thought styles: when diverse thought communities meet, they may have concerns about fully understanding each other and can be mutually labelled as heretical

or inconsistent. This last point is particularly relevant to this study because Fleck proposed a 'weak' notion of incommensurability (see Peine, 2011), in which the communication of ideas between diverse collectives – that is, the inter-collective sharing of thought – points to a relevant dimension of refused knowledge production. For Fleck, there is no fundamental distinction between scientific and other forms of knowing. Instead, what is at stake is the need to capture the different forms of knowledge production that, in the case of communities mobilizing refused knowledge, can evolve in pluricentric practices comprising experiential expertise and remedies (rather than standardised methods and formal research protocols) and sometimes the ambivalent exploitation of argumentative repertoires and explanatory rhetoric pertaining to prevalent scientific domains.

The notion of thought style was primarily adopted by science studies scholars and social theorists to understand the social dynamics involved in the constitution of diverse scientific fields and biomedical domains (Löwy, 1990, 2004; Hacking, 1992; Rose, 2007; Wahlberg and Rose, 2015). It helps us theoretically capture the ways in which concerned communities mobilise cognitive and material resources located in a field of knowledge that is partially or entirely antagonistic to institutionalised biomedicine without conferring on it an intrinsic epistemic dominance, as suggested by the symmetry postulate. In this way, our study contributes to the debate about the development of models of caring and healing that diverge from the biomedical paradigm, offering valuable insights into current forms of resistance against scientific and biomedical models and explanations.

Methodological Framework: Locating Refused Knowledge in the Context of the COVID-19 Pandemic

This research was based on qualitative case studies of three Italian communities engaging in the production of refused knowledge of how to take care of the human body during the COVID-19 pandemic in several online settings.

The first case study concerned the Italian Five Biological Laws (5BL) community, a heterogeneous group of followers of so-called Germanic New Medicine (GNM), a complex system of knowledge that purports to be able to cure cancer, among many other diseases, and is rejected by allopathic practitioners for having no scientific basis. GNM is a self-vindicated medical paradigm developed in the 1980s by Ryke Geerd Hamer, a German ex-physician whose licence to practise medicine was revoked in 1986 for having treated several patients using methods that resulted in irreversible damage or death. Despite the serious concerns about the reliability and safety of GNM, the 5BL approach has gained momentum in Italy; for example, before his death, Hamer recognised Italy as one of the countries with the greatest penetration of GNM users and practitioners (D'Amato, 2019).

The second case study concerned the ‘alkaline water’ community, which comprises various groups promoting an alkaline diet to minimise the risk of metabolic acidosis, which is considered responsible for many diseases, including cancer and diabetes. For some years, there have been devices for domestic use on the market that produce ‘alkaline ionised water’ from tap water. These devices are promoted by holistic practitioners who recommend drinking alkaline water to establish a chemical–physical balance in the body’s cells and tissues. According to these promoters, acidity in the cells and tissues is the leading cause of the most widespread diseases in Western countries, such as cardiovascular disease, diabetes and cancer. However, the alleged benefits have not been supported by scientific evidence (Fenton and Huang, 2016; Morganti *et al.*, 2017). Nevertheless, the alkalinisation of diet to prevent diseases and treat cancer is supported by some academics and professionals working in Italian healthcare institutions.

The third case study explored the refused knowledge emerging in the Italian community formed under the label ‘No-5G’. This community opposes the fifth-generation (5G) standard for broadband cellular networks due to its alleged negative impact on well-being. Although the most important health institutions, such as the World Health Organization (2020) and the Italian National Institute of Health (Polichetti 2019), have affirmed the safety of 5G, the No-5G community claims that exposure to electromagnetic waves can weaken the immune system and cause several pathologies (e.g. cancer or electromagnetic hypersensitivity).

Each of the three case studies was first conducted as an instrumental case study (Stake, 1994) to provide insights into the emergence of a model of healing and its substantive refused knowledge. The three case studies were then treated as a whole, or as a collective case study (Stake, 1994), to gain a comprehensive understanding of the conditions under which refused styles of thought can be rendered actionable in everyday life. The selection of the three case studies was based on the following criteria: (1) communities engaging in producing formalised (or formalisable) knowledge in the fields of health, care and well-being; (2) communities rejecting all or part of the explanations that the scientific establishment offers for many COVID-19 pandemic-related phenomena; (3) communities advocating independence from medical associations and healthcare institutions and professionals; and (4) communities critically assessing the possible dynamics of subsumption by prevalent biomedicine and not recognising formal qualification paths or statutory professional regulations.

It should be noted that while the three studied communities share a general tendency towards social change, especially concerning the authoritative position of scientists and healthcare professionals in society, they do not share a ready-made, authoritative set of political arguments or a general theory of social transformation. Thus, such communities resist being conceptualised as

traditional (social) movements. Therefore, we use the term ‘community’ to account for a relatively stable yet fluid group of people who share self-care and well-being practices and aim to lend credibility to claims generally rejected by the institutional scientific community.

Data collection began in February 2020, when SARS-CoV-2 entered the online discursive arena, and ended in October 2020. Since the studied communities have a strong presence on social media, we conducted the data collection exclusively online, following the principles of web ethnography outlined by Hine (2004). To select the appropriate online settings, we performed preliminary queries on search engines and social networks concerning the three communities. This allowed us to identify the most relevant sites, such as blogs, instant messaging groups, and Facebook groups, characterised by high levels of interactivity. During non-participant observations, we further iteratively and recursively refined the study setting to retain the more interactional online settings and exclude the less active ones. Following publicly available conversations, reposted content, and public invitation links to social media based groups, we finally obtained a sample of more than 50 online spaces, including 13 open personal Facebook profiles, 12 Facebook pages, 13 Facebook groups, 3 YouTube channels, 9 online blogs/websites, video lessons and Zoom webinars, 2 LinkedIn pages, 1 WhatsApp group, and 1 Telegram channel, which we accessed via public links posted on Facebook.

As Zayed (2021, p. 60) recently noted, the practice of sharing public links to access online groups or instant messaging chats creates the expectation that anyone can join the conversation. This perception is reinforced when members see others occasionally join an online setting or leave en masse. This aligns with the ethical principle widely embraced by social scientists conducting online fieldwork that online observations should take place when and where people expect to be observed by strangers (Fuchs, 2013).¹ All the online settings included in this study were publicly accessible. We opted not to engage in discussions or otherwise interact with the followers of the three communities and to conduct only non-participant observations, collecting publicly available content. In the absence of standardised rules, as ethics guides fail to keep up with innovations in digital and social media environments, scholars have been calling for a flexible and ‘situated approach to online research ethics’ (Hine, 2017, p. 404). The mutability, ambiguity and situatedness of ethical issues in web ethnography prompts a return to the golden rule of ‘do not harm’ (Barbosa and Milan, 2019, p. 57). This means that researchers should take care to protect studied subjects regardless of space publicness. Accordingly, to safeguard the participants’ anonymity, we used the pseudonymising de-identification technique, which consists in replacing all identifying information with pseudonyms while maintaining the analysability of data (Mancosu and Vegetti, 2020).

To collect ethnographic field notes, we used a shared template to draft weekly diaries that allowed constant comparisons, for example, of health-related practices or discourses about public health measures. We coded the empirical material during and after the fieldwork according to the principles of constructivist grounded theory (Charmaz, 2009), which facilitated an iterative and reflexive process of data analysis. In presenting our findings, we followed the approach proposed by scholars such as Jackson (1990), Rapp (2011) and, more recently, Lewis *et al.* (2014). According to this approach, in this paper empirical data are not merely treated as free-standing pieces of information but as empirical triggers used to describe and analyse online settings. This allowed us to trace the process of refused knowledge production across several online settings to capture the constitution of refused styles of thought.

This study was part of a broader project on the social conditions and processes affecting the acceptance of knowledge partially or entirely rejected by institutional biomedical and scientific authorities. This project was approved by the Ethics Review Board of the University of Padova (approval no. 2020-Ill/13.41.1).

Empirical Analysis: Exploring Pandemic-related Refused Styles of Thought in the Making

Experiencing with the 5BL to Face Pandemic Times

Germanic New Medicine (GNM) can be described according to its peculiar structure of knowledge developed in relation to assumptions of the Five Biological Laws (5BL) community. Well-being and self-care practices are informed by interpretative work directly conducted by 5BL followers, in which symptoms of malaise (e.g. fever or breast pain) are transformed from one type to another, and a specific malaise is distinguished by inferring a specific psychological conflict (i.e. so-called Dirk Hamer syndrome) that causes a 'biological lesion' in a specific area of the brain, which, in turn, causes the symptom (see Hamer, 2005). Proponents of the 5BL claim that diseases, as defined and classified by allopathic medicine, as well as their clinical manifestations, diagnoses and control, are based on fundamentally erroneous knowledge of human biology. In their view, every malaise is the manifestation of a 'Meaningful Special Biological Programme of Nature' (Hamer, 2005, p. 2) and does not need to be addressed with therapeutic protocols. Instead, it should be left to run its course because it always has the virtuous biological purpose of restoring the individual's healthy status – that is, resolving the conflict in the body.

Our empirical data illustrate how followers of the 5BL approach, in elaborating refused knowledge, analysed the allopathic medicine response to the pandemic as a form of 'biological' and 'statistical reductionism':

I don't want to talk about data per se because things are evolving and will only be clearer at the end of this situation. I want to talk about something important that is missing from the mainstream understanding of this scenario. We should look at the blind spot of today's molecular medicine, a kind of medicine made of big data, beyond which what is not measured is considered insignificant. There is much more than just numbers. An intensive care unit bed is not just a bed – it is not just a number; it is a person. [...] We are no longer able to look at reality without the filter of data and machinery that claim to simplify a complex reality. [...] We have the feeling of being in control of this reality that medicine translates into data. [...] It's a blind spot because the data exclude that gigantic portion of unquantifiable reality. Is there still someone who wants to go and see the virus in all this? (Excerpt from a video by MS posted on a major Italian blog about GNM and shared on several Facebook pages promoting the 5BL)

The 5BL proponents outline a distinctive discourse that, to a certain extent, presents certain areas of overlap between GNM and the contemporary holistic medical theory, especially with regard to criticism of the Cartesian mind–body dichotomy in which the modern medicine is rooted (see Foucault, 1973). The main characteristic of 5BL refused knowledge–based style of thought is the tendency to refute the epistemological basis on which the interpretive and clinical lenses of the biomedical sciences are based. More specifically, it is a discursive strategy that the 5BL proponents mobilise to construct a normative narrative that frames the prevailing biomedical style of thought as inherently unreliable. In this view, biomedicine does not serve public health because living bodies and well-being itself cannot be reduced to mere numbers or statistics.

Like lay perceptions of medical science (Vuolanto *et al.*, 2020), 5BL-based refused knowledge is entrenched in a contentious relation with institutional biomedical practice, which is considered a domain of mere technological expertise that is unable to meet ethical standards or acknowledge individuals as emotional and communicative human beings. Thus, the 5BL proponents consider physicians and healthcare professionals as engines of a 'pandemic politics of fear'. In their view, physical distancing measures, stay-at-home orders, and lockdowns can inflict a diffuse psychological shock on the population, thus inducing a state of malaise that the biomedical community considers to be related to COVID-19. In the context of the 5BL community, the pandemic is considered to be a political tool in the hands of prevailing medical elites to subdue human behaviour and govern public health based on unfounded claims about a supposed global infectious outbreak. This point clearly emerges from a discussion in a Facebook profile managed by GB, one of the most prominent 5BL advocates:

If you would like to share your mask experience, I would be grateful. (Post on Facebook profile by GB)

The link to the shared article was accompanied by an excerpt:

This short article [...] presents a hypothesis to be verified in your everyday life related to a phenomenon that can be criticised or not, for which state policy requires people

to wear face masks covering the nose and mouth to avoid infection with the notorious and criminalised Coronavirus.

The post triggered 86 Facebook mask-related comments:

The first time I put it on, I took it off after 10 min. Many dots appeared immediately on the right side of my cheekbone, and the skin was a little red. For me, it is a symbol of gagging, of submission. I do not tolerate it, so even my skin does not tolerate it! (LS)

I only wear it if the people close to me are afraid. But I can't breathe. [...] I suffer from shortness of breath, and I have to take it off. In the office, I am far from my colleagues, so I don't use it. (OE)

My son had to wear it from the beginning of the 'pandemic' for work reasons. After a few days, he developed a very large sore on his nose at the point of contact. (RP)

Proponents of the 5BL have cultivated a form of self-responsibility for the everyday care of one's body and psyche during the pandemic, outside the jurisdiction of medical expertise. This seems to reverberate with the mainstream discourse on so-called personalised healthcare, in which individual health quality (traditionally linked to top-down public policies) is increasingly considered a matter of individual experiential expertise and self-awareness (Topol, 2015). Performing self-responsibility is related to acquiring and sharing self-experienced knowledge through public storytelling and documentation of individual events related to health and discomfort. This is a crucial point in the shaping of a refused-style of thought that involves situated patterns of learning and practising a body of refused knowledge. Such practising is intended to be a 'self-discovery tool' for becoming aware of the functioning of one's own body, thereby critically assessing medical knowledge of the declared pandemic.

In so doing, 5BL followers believe that they can co-produce actionable cognitive tools to appease fear so that they avoid states that mainstream medicine could consider as signs of COVID-19. This requires them, as expected by 5BL assumptions, to be alert so that they can discover the psychological origin of their discomfort and malaise. Their experiential expertise in producing and sharing refused knowledge allows them to deconstruct what biomedicine calls a health crisis (i.e. the pandemic) and demonstrate the epistemic solidity of the 5BL. Thus, they aim to collectively consolidate and mobilise actionable experienced knowledge to maintain a healthy body in everyday pandemic life. Analytically speaking, 5BL proponents profess the development of an everyday health knowledge through which the individual – by verifying the reliability of the 5BL and sharing its outcomes with the community – can become an experiential expert, thus breaking the monopoly of institutionalised medicine on health and illness.

In the studied online settings, the 5BL community shapes counter-subjectivation trajectories aimed at sustaining a refused style of thought, where

experiential knowledge plays a pivotal role in the reappropriation of individual health agency. The shaping of refused knowledge cannot be framed as the signature of a process that, in McIntyre's words (2018, p. 9), leads to an 'eclipse of truth'. On the contrary, the reappropriation of individual health agency implies endorsing social values that accord a central place to the self as the origin of the truth about one's body. Here, the issue at stake does not concern an a priori rejection of any knowledge pertaining to the prevailing biomedical paradigm. Rather, 5BL proponents claim the need to directly engage their own body in producing and verifying knowledge reliability.

Instead of a straightforward rejection of science and rationality as argued in the context of mainstream post-truth theories (Ball, 2017; d'Ancona, 2017; Davis, 2017; McIntyre, 2018), this highlights an epistemological line of demarcation between the 5BL theory and the prevailing biomedical paradigm. Instead of clinical or laboratory evidence, the 5BL approach attaches a privileged status to personal experience and peer interactions, which are considered the sources of reliable knowledge of how to address health issues. Like people engaging in conspiracy theories (Harambam and Aupers, 2017) and alternative models of healing (Vuolanto *et al.*, 2020), 5BL proponents promote a public image of the community as an assemblage of critical and free thinkers who actively scrutinise biomedical knowledge and refuse to subordinate individual health decision-making to institutional medical professionals.

Experiencing with Body Alkalinization for Well-being in Pandemic Times

Since the early period of the COVID-19 pandemic, 'alkaline well-being' promoters have exploited online settings to reach new and broader audiences. Consequently, web ethnography allowed us to examine how members of the Italian community advocating the benefits of an alkaline diet disputed some of the main scientific claims about the pandemic, outlining specific actionable ways to take care of their health. This community rejects the recognition of pathogenic agents as the primary causes of diseases. Accordingly, it does not recognise SARS-CoV-2 as the primary cause of COVID-19. Rather, the symptoms of COVID-19, as in the case of other diseases, are attributed to a disruption to the organism's chemical balance that allows viruses to infect it.

The argumentative strategies employed by the promoters of alkaline water to support shared knowledge in this community are ambivalent. Although promoters extensively use practices typical of scientific communication (e.g. webinars, demonstrations of liquids' properties as a function of their pH, quotations from scientific experts and references to the academic literature), their narratives are firmly rooted in the holistic culture developed in complementary and alternative medicine domains. Thus, on the one hand, they use the argumentative strategies of institutional science to legitimise the (refused) knowledge about the health power of alkaline water and the beneficial effects of

alkaline diet; on the other hand, they deny the scientific evidence mobilized by medical expert during the pandemic to refute the health power of alkaline water. The core argument is that SARS-CoV-2 can infect the body not because of its biological characteristics but because humans are used to ‘acid’ and ‘unhealthy’ lifestyles that threaten the body’s equilibrium, as well as the balance between humans and natural ecosystems. In this refused style of thought, the health crisis offers the opportunity to promote body alkalisation practices as a way of strengthening the immune system. Indeed, the respiratory symptoms of COVID-19 are attributed to malfunctioning or weakening of the immune systems caused by excessive acidity in body tissues:

It seems plausible to assume that the gut is the cause or that it aggravates SARS-CoV-2 infection. The respiratory tract hosts its microbiota, but patients with respiratory infections generally present with intestinal dysfunction, which is related to a more severe clinical course of the disease, thus indicating a relationship between the gut and the lungs. This phenomenon can also be observed in patients with COVID-19. [...] Treating the intestinal microbiota can be a new therapeutic option or at least an adjuvant therapeutic choice. (Post on Facebook page by SM, doctor and promoter of alkaline water)

Several members of the alkaline community criticise government measures to respond to the health crisis as further restrictions on personal freedom. The so-called ‘system’ – the government and allied scientific communities, along with Big Pharma and the biotech industry – is considered responsible for the usurpation of individual agency in matters of health and well-being. Opposing the ‘system’ is viewed by alkaline water supporters as a trigger to intensify activities aimed at standing up to institutional science via an ‘awakening of conscience’. Indeed, alkalisating the body is considered both a healthy and training practice to build awareness of the need to oppose a ‘system’ that promotes unhealthy and dangerous lifestyles:

At the end of this story, [...] we will realise and take stock [...] against the SYSTEM THAT WANTS YOU TO BE A SLAVE AND SICK! Defend your health and learn to distinguish the truth from the lie! (Post on Facebook page by MD)

What is your mission? The ‘awakening of conscience’ is an individual action that consists in the re-emergence of what everyone has in their Deep Self. [...] The period we are experiencing has created a greater awareness of who we are, how we invest our time and what our tomorrow will be. (Post on Facebook page by MD)

Like conspiracy theories (Harambam and Aupers, 2015; Harambam, 2020a), the promotion of ‘alternative lifestyles’, such as drinking alkaline water, becomes a reaction against the system that endorses institutional science. Proponents of body alkalisation practices oppose the relationship between scientific knowledge production and vested interests and the exclusion of other forms of knowledge by scientific experts who constitute a global ‘power elite’ colluding with politicians and the media in support of dogmatic knowledge.

In their view, the alteration of acid–base balance of the body’s tissues becomes a representation of a human-nature-society balance compromised by institutional science. Hence, an alternative lifestyle as a body care practice is a critical stance towards prevailing science. The alkaline community does not question only the knowledge disseminated by experts but also the institutional and social status on which their authority is based. Drinking alkaline water is considered both a body self-care practice and a strategy for developing awareness of and resisting what they identify as a ‘health dictatorship’ – a coalition of powerful groups (governments, scientific institutions and biotech firms) controlling people. Accordingly, the alkaline diet is considered a regimen that prevents viruses and bacteria from attacking the body and thus an alternative to antibiotics and vaccines.

Antibiotics and vaccines are seen as tools used to alter the natural chemical balance of citizens, and consequently, to make them sick. Within the alkaline community-based style of thought the strengthening the immune system through the alkaline diet becomes a form of resistance to the political and social oppression imposed by an unhealthy system:

How do you explain the different reactions between individuals? The reason is ‘immune resistance’. Those with strong immune systems are less likely to get the disease. [...] The only valid way to defeat the disease is to strengthen the human immune system. [...] Using antibiotics and vaccines is contrary to the laws of nature. Bacteria and viruses will always outnumber us. What strategy is in line with nature? It is called Preventive Medicine. The key to succeeding in this endeavour lies in daily lifestyle and the health of the intestine. (Post on Facebook page by MD)

In the context of the COVID-19 pandemic, this community views the body as a field of bitter struggle against the alleged dictatorship of institutionalised science. Taking care of the blood and cells is an act of opposition to mainstream scientific culture. Thus, the claims about alkaline water in online settings serve to foster personal change while emphasising individuals’ responsibility to manage their own health in opposition to the system and the economic, political and scientific institutions that support it.

Experiencing with Self-protection Against 5G Technology in Pandemic Times

The debate on whether daily exposure to electromagnetic radiation has adverse effects on human health (see Polichetti, 2019; National Toxicology Program, 2018) can be traced back to the 1950s, when physicians in Eastern Europe first described a radio wave sickness (Sadchikova, 1960; Glaser, 1984), more recently dubbed *electromagnetic hypersensitivity syndrome* (EHS; see Genuis and Lipp, 2012, p. 105). To prove the adverse effects of electromagnetic field exposure and gain social recognition, people suffering from electro-hypersensitivity engage in a range of activities that, to a certain extent, are borrowed from

scientific knowledge-production practices, such as surveys for collecting clinical records and health self-monitoring.

These practices are similar to those performed in self-tracking communities, in which lay-people use scientific procedures to elaborate knowledge for self-use in their everyday lives. For example, just as self-trackers identify relationships between certain variables, such as the influence of various foods on sleep quality and productivity (see Heyen, 2020), electro-hypersensitivity sufferers conduct self-monitoring to test and demonstrate the impact of various electromagnetic devices on their psychophysical health. Along with self-monitoring practices, they build strategic alliances with critical medical experts (Falcioni *et al.*, 2018). In this way, they aim to assign diverse complaints and symptoms to standard categories (de Graaff and Bröer, 2012) and to consolidate the risk of electromagnetic wave exposure as a socially recognised concern (Heyman *et al.*, 2010).

Recently, hypersensitivity sufferers have coalesced into the broader community called ‘No-5G’, which aims to question the deployment of the 5G antennas that are considered to be responsible of the propagation of particularly harmful electromagnetic waves. The No-5G-based thought style is grounded on the belief that the experiments conducted by scientific institutions for assessing the safety of the 5G infrastructure are fallacious and influenced by economic interests. From the No-5G point of view, the only way to properly manage one’s well-being is to independently take responsibility for one’s care, breaking free from the so-called ‘system’ – devised by governments, mainstream media, Big Pharma and institutional medicine – which is considered to subject health to the capitalist logic of profit. In their perspective, among the already mentioned fundamental players of this ‘system’, particular emphasis is given to IT companies that are investing in and promoting the 5G infrastructure. Such companies are considered to be primarily engaged in developing increasingly invasive and harmful technologies to allow political élites to implement a pervasive control of the citizens. In this respect, within the No-5G community, it is widely believed that protecting one’s health primarily means learning to manage the interactions between the human body and the many technological artefacts flooding daily life.

During the pandemic, No-5G followers endorsed the belief that electromagnetic waves were one of the main causes of the spread of SARS-CoV-2. According to our findings, the No-5G community tries to demonstrate that electromagnetic fields can suppress the immune system, making people much more vulnerable to attacks by pathogens entities:

Huawei, which developed 5G technology in defiance of any public health risk assessment, has donated protective suits, masks and even Wi-Fi infrastructure to hospitals. This is idiocy because radio frequency weakens the immune system and should definitely be banned from health centres. (Post on Facebook group Stop5G ITALIA by FG)

Since the beginning of the pandemic, the No-5G community has engaged in co-producing interpretative lenses through which they can make sense of what they consider a chaotic, frightening, and uncertain situation. Accordingly, the community has targeted pandemic-related scientific uncertainties surrounding the origin of the virus and the relative lack of effective care protocols to combat COVID-19.

As previously mentioned, it is essential for members to learn how to manage the interactions between bodies and technological artefacts: this becomes even more important during the spread of the virus, since – from their perspective – electromagnetic waves emitted by the 5G antennas weaken the immune defences. During the observation of the online settings, users exchanged advice, such as disabling data traffic on a phone when not in use, turning off the phone or modem when possible or preferring a network cable to connect to the internet. By participating in community conversations, people also learn about self-made and self-experienced tools designed to shield domestic environments from electromagnetism, such as aluminium electromagnetism-blocking curtains. However, the management of the interactions between the body and technological artefacts takes place not only inside the home but also in public spaces, where people have less control over electromagnetic sources.

Indeed, according to the No-5G proponents, the only efficient way to protect oneself from electro-smog outside the home is to stay away from 5G antennas. However, to avoid these antennas, one must first be able to recognise and distinguish them from other types of antennas: this requires practices such as sharing photographs and indicating the positions of antennas via geolocation. Moreover, No-5G proponents frequently report symptoms of EHS in WhatsApp groups.² This is performed as a kind of self-care literacy activity:

Pay attention to the first alarm bells set by your body. Usually, cartilage and the skeletal system receive fewer nutrients and start to have problems. (Message in WhatsApp group by EM)

Thus, members learn how to safely use – or reject – electronic artefacts and medical products, particularly the anti-COVID-19 equipment recommended by institutions. This involves classifying non-electromagnetism-related devices as ‘healthy’ or ‘unhealthy’, which requires the mobilisation of experiential expertise that allows community members to understand which items or entities should be used in daily life and which should be rejected as unhealthy despite being recommended or even imposed through contagion containment measures. For instance, entities such as vitamin C or plasma for serotherapy are considered healthy, whereas masks, disinfectants and vaccines are regarded as unhealthy. According to some No-5G followers, masks are very harmful because they cause hypercapnia, and gloves facilitate the proliferation of viruses and germs on the skin. Moreover, disinfectants that

are commonly used for hand washing weaken the natural immune defences of the body:

If the mask is not changed every 3–5 min, a continuous bacterial aerosol mechanism is set in motion. Wearing gloves causes the proliferation of germs on the skin because of the lack of ventilation, and this weakens our immune defences. (Message in WhatsApp group by GM)

The classification of anti-COVID-19 equipment stems from the common belief among No-5G followers that it is necessary to rely on self-experienced knowledge as a way to restore the centrality of individuals in decision-making for the management of health issues and one's living body in general. Thus, by refraining from using the anti-COVID-19 equipment recommended by institutions, the community positions itself against the prevailing biomedical thought community. In the case of the No-5G-based thought style, refused knowledge production is made possible predominantly by peer interaction in online spaces. Interpretative models, anecdotal and self-experienced evidence, and everyday solutions are offered to cope with the pandemic, which, according to the No-5G community, is closely linked to electromagnetic pollution. In these online spaces, community members feel that they can obtain truthful information about such diseases as COVID-19 or EHS and about how to protect their well-being in an unhealthy environment. In their view, this is crucial since the medical institutions and experts entrusted with the health of citizens are considered as unreliable, given that their knowledge and assumptions cannot be directly verified.

Conclusion

Drawing on qualitative web ethnography case studies, this research explored how different communities collectively create refused knowledge regarding the pandemic. The knowledge we studied is defined by these communities as totally or partially 'refused' by institutional science. In this regard, by avoiding assigning an a priori dominant position to prevalent science and biomedicine, this study considered how refused knowledge making practices can be an analytical entry point for exploring the current forms of opposition to and negotiation with institutionalised science. In doing so, we analysed how the relationship with scientific knowledge and technical expertise is reconfigured by those who are suspicious or distrustful of science.

Our study sheds light on what communities relying on a body of refused knowledge think about pandemic-related health and illness issues and what they do to render such knowledge relevant and potentially actionable in everyday life. Fleck's (1935) notion of style of thought has been critical in grasping the different forms of refused knowledge production that, in the case of the communities scrutinized in this paper, encompassed experiential

expertise and remedies and sometimes the ambivalent exploitation of content and explanatory strategies pertaining to prevalent scientific domains. By aligning style of thought with the symmetry principle as recently rediscussed in the field of STS (see Lynch, 2017, 2020), we examined refused knowledge-making practices without privileging any kind of statement over others or normatively labelling particular claims as true or false, successful or mistaken.

In this way, we explored the shaping of claims that are partially or completely rejected by biomedical authorities and examined how such claims and experiential expertise are co-produced and then enacted in everyday life by concerned communities of people. A crucial point we underlined is related to the fact that disputing prevailing science takes place at both the epistemological and socio-cultural levels, where communities' members shape and share refused knowledge in an ambivalent relationship with science and various epistemic institutions. Thus, differing social values and objectives result in mutual incompatibilities or conflicts between incommensurable ideas, while in other cases disagreement is partial.

Our findings reveal two main interrelated dimensions of self-experienced knowledge-based styles of thought: (1) the use of experiential expertise to reframe the body in a process of self-care, thus validating a corpus of refused knowledge through direct personal experience; and (2) narratives of demarcation of communities' thought styles with respect to the prevalent biomedical paradigms as a way of gaining experiential epistemic autonomy. The first dimension highlights the centrality of learning and experiential expertise in living outside or on the margins of institutional healthcare.

Indeed, the concerned communities elaborate a conception of the human body as a setting in which the individual's agency in health decision-making can be reappropriated. When the experiential knowledge of community members is shared and combined, a communal body of knowledge emerges, which can be solidified as a constitutive resource of the refused style of thought in question. This is an exploration of and collective learning about one's own body, which involves acquiring and self-experiencing refused knowledge in everyday life. In refused styles of thought, the 'effectiveness' of refused claims and beliefs is constructed in a way that enables laypeople to directly experience the epistemic credibility, reliability, and effectiveness of such refused knowledge.

What and how a thought community's members see and think depend on experienced knowledge collectively produced through peer interactions. Community's members are simultaneously the producers and subjects of epistemic certification practices and see self-experienced knowledge as a particular way of knowing about their bodies and health. Moreover, they view biomedical practitioners as actors driven by interests that conflict with public health interests. In response, they try to optimise their bodies and achieve a level of well-being that, in their view, biomedicine is unable to offer.

By mobilising experiential expertise, the corpus of knowledge in which the refused thought style is rooted can be consolidated and gain epistemic authority in the eyes of communities' members. The process of configuring one's own living body as a locus for experiencing knowledge with a refused style of thought constitutes a form of knowledgeable doing that involves specific experiential expertise and self-diagnostic techniques. Hence, experiential expertise enables the production and consumption of knowledge, eroding the distinction between producers and users of knowledge. Accordingly, experiential expertise and self-testing the reliability of refused claims are recognised as epistemic devices for certifying actionable knowledge. In this regard, in line with a previous study on the way in which conspiracy theories dispute scientific authority (Harambam and Aupers, 2015), members of the communities scrutinized in this paper collectively engage in an effort not only to deconstruct institutional scientific claims and explanations but also to produce and share their own refused knowledge and theories in diverse online settings.

The aspect described above is closely related to the second dimension, which orients the everyday actionability of the refused style of thought. Demarcation narratives allow prevalent biomedical methods, practices, and organisations to be excluded from the domain of epistemic authority because this kind of authority should be reserved for genuine experiential practitioners who can directly verify the reliability of certain claims. Since demarcation strategies do not a priori exclude the mobilisation of knowledge produced in the context of prevalent biomedical science, they establish a weak de facto incommensurability between the refused style of thought and the scientific paradigm. More specifically, our findings show that demarcation can be rooted in a strategy that involves one or more of the following elements: (1) employing one's own experiential expertise and knowledge in relation to biomedicine and other scientific fields; (2) appropriating biomedical language and scientific terminology; and (3) increasing the reliability of the thought community by enrolling or mobilising 'outsider' scientific experts.

Overall, by establishing experiential epistemic autonomy, demarcation strategies go beyond qualifying a refused style of thought as a way of knowing according to certain forms of explanation that contrast biomedical sciences. Crucially, these strategies also concern the very content of what is to be explained. That is to say, demarcation shapes and establishes a novel object of explanation, circumscribing the set of problems, issues and phenomena that communities relying on a body of refused knowledge attempt to elucidate.

Notes

1. This principle has recently been endorsed by the British Psychological Association (2009) and by the British Sociological Association (2016).

2. In this case study, WhatsApp (along with Telegram) proved to be the most relevant online space in terms of interaction and refused knowledge production because of mainstream social media bans on No-5G-related content.

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Contribution statement

- ◆ Stefano Crabu: Conceptualization (lead); methodology (equal); writing – original draft (equal); data curation (equal); formal analysis (equal); editing (lead); Writing – Review & Editing (lead).
- ◆ Ilenia Picardi: Conceptualization (supporting); methodology (equal); writing – original draft (equal); data curation (equal); formal analysis (equal); editing (supporting); Writing – Review & Editing (supporting).
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