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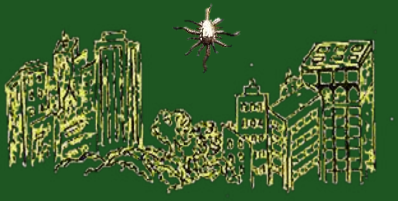

Healthcare and Public Health: Questions of Legitimacy

Edited by Italo Pardo and Giuliana B. Prato

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Special Issue *Healthcare and Public Health: Questions of Legitimacy*
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On Legitimacy, Healthcare and Public Health

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This Special Issue on *Healthcare and Public Health: Questions of Legitimacy* brings to the reader short essays that originate in the contributions to the invitation-only Workshop on 'Legitimacy: The Right to Health' that we organized in September 2021 in Tuscany, Italy, under the auspices of the International Urban Symposium-IUS. Here, cross-cultural ethnographic knowledge contributes to taking the extant scholarship around legitimacy into the study of healthcare and public health. Addressed ethnographically through the lens of legitimacy, the focus on this highly significant area of studies, and of life, advances our understanding of complex dynamics and their impact on 'ordinary' people. The analyses inspired by this conceptual framework extend to what the pandemic has revealed about different societies and settings.

The aforementioned Workshop was a key part of an overall project in which *legitimacy* is the central organizing concept. Started in 2019, this project is driven by intellectual concern on the complex issues raised by growing world-wide mismanagement of healthcare and public health. Because of the Covid-19 pandemic, the Workshop, originally planned for September 2020, was postponed to September 2021, when it benefited from the work of a strong field of scholars from various countries who are at different stages of their academic careers. Sharing the anthropologist's natural aversion for unjustified abstraction (Leach: xvi ff.; Harris 1986: Chap. 1), they contributed analyses based on regionally diversified ethnographic knowledge from Europe, the USA, India, Africa, Latin America and the Far and Middle East, shedding, in the process, powerful light on the inequities and erosion of responsibility, trust and authority that pollute this critical field worldwide.

In spite of the disruption caused by pandemic-related international restrictions, the Workshop took place efficiently, thanks to a generous grant from the Wenner-Gren Foundation for Anthropological Research (Gr.CONF-856) and to the intellectual and organizational know-how, and network of the International Urban Symposium-IUS. The organizers' local knowledge helped to secure fine accommodation, food, work facilities and socializing events. Over the week that we spent together, we became a truly engaged and close-knit group of human beings actively engaged in developing ideas, exchanging constructive criticism and identifying synergies and complementarities. Making the whole exercise successful intellectually and socially, useful new analysis and exciting ideas were seeded and debated, which bodes well for future developments in this field.

This Special Issue is the first of two publications springing from the overall project. A second publication is forthcoming in the Series 'Palgrave Studies in Urban Anthropology' as a volume that brings together full-length chapters (Pardo and Prato eds 2023).

The brief articles that follow — as, of course more extensively, the full-length essays in preparation for publication — have benefited from the extensive discussions that took place during the meeting. Some participants had previously met and interacted intellectually, others had not. The opening ice-breaking reception, the general atmosphere of informality, the participants' dogged engagement with the topic, the smooth-running organizational set up and the hospitable venue all contributed to the success of this exercise. In early July, the draft papers were circulated among the group, who read them in advance of the meeting. Therefore, during the meeting the papers were discussed in great detail, not presented. Extensive written comments on all papers and detailed reports were produced and subsequently circulated among the group.

We witness daily reports from around the world of increasing discontent among ordinary people with those in power, from a variety of political perspectives. This dissatisfaction highlights the long-standing conflict between rulers and ordinary citizens. Comforted by the strength of long-term field research in classic anthropological fashion (Pardo and Prato eds 2017), our analyses draw heavily on the anthropological literature on legitimacy and legitimation — of morality and action, of the law, of politics and governance — to investigate the empirical realities that qualify the good-sounding claim made by various systems, including democratic systems, across the world that people's health and well-being are a priority. We aim to contribute to the further development of what, since the mid-1990s, has grown into a sophisticated international debate (Pardo 2000; Pardo 2000 ed.; Pardo and Prato eds 2018; Pardo and Prato 2019; Pardo and Prato eds 2019a, 2019b). Our discussions benefit from in-depth knowledge of ideas of legitimacy at the grassroots to examine the impact of legislation that turns patients into clients and the disruptive ramifications of unscrupulous practices (at local, national and supranational level) that may or may not break the law, and to explore conflicting moralities across the social, cultural, professional, economic and political spectra.

From challengingly varied ethnographic angles, we debate the progressive erosion of the legitimacy of professional and political authority worldwide, endeavouring to address important questions about healthcare and public health, including the impactful mismanagement of the urban environment extending to the pollution of soil, water and air, and to the collection and disposal of rubbish. We strive to provide insights into the complex ways in which healthcare and public health authorities gain, keep or lose the public's trust, both in 'normal' and 'crisis' situations. In doing so, we keep a keen eye on the impact of the current pandemic on urban life — recently examined in Supplement 4 to this journal (Prato ed. 2020) — on its inequalities — extensively discussed in Pardo and Prato (eds 2021) and Spyridakis (ed. 2022) — and on the ever-expanding gap between rulers and the ruled. We ask what a healthy society means for the rulers and address how their views are translated into social policies.

Across the world, the powers-that-be appear to be oblivious to the importance of understanding and addressing dodgy actions by powerful individuals and lobbies. We refer specifically to actions that do not strictly break written rules because they are not adequately dealt with by the existing legislation or, in a growing number of cases, because they are made to be legal through expedient changes in the law (Pardo 2000). Our analyses are cogently aware that in the field of health, this issue is graphically magnified because, here, people are at their most vulnerable (Pardo 2004). We recognize that the pandemic has 'simply' brough into stark light the acute crisis of responsibility and accountability in public life that mars many democracies. The current debate on legitimacy and legitimation undergirds precisely this analytical imperative.

Identity, money, ideology, politics, socialising, living conditions generally are all important aspects of people's lives on which good governance is tested at the grassroots. There are, however critical areas of associated life where the legitimacy, and by extension the authority of a government stands or falls. As the analyses demonstrate, healthcare and public health and safety fall squarely in this category. What matters most to the ordinary man and woman is their own well-being and the well-being of the people they love. In ethnographically varied settings, we find that the mismanagement of healthcare and public health is the ultimate litmus test for the legitimacy of the authority to rule. We find that in this field, especially, the very legitimacy of the institutions that are responsible for the decisions and actions that deeply influence people's lives is at stake. As we read through the essays collated here, we see that all too often those institutions are been found wanting; and we see how the Covid-19 pandemic has brought graphically to light critical failures in this field.

From Giuliana B. Prato's comparative reflections on healthcare, we learn of variations in 'access' to healthcare between Italy and the UK, and within each country, and of how healthcare ethics has changed from a charitable and 'holistic' approach — whereby healing addressed a person's body, mind and spirit — to the fulfilment of statistically quantifiable indexes of the healthcare systems' efficiency and resilience. The discussion is contextualised historically looking at the underlying ethics that led to modern policies on the provision of 'free' healthcare and the protection of health both as a fundamental individual rights and as a service to the whole community. Then the analysis addresses the increasing marketization of the healthcare and how its negative effects have been exacerbated during the Covid-19 pandemic. The critical issue of privatization and ensuing commercialization links directly to the essays by Pardo on Italy and Koenig and Diarra on Mali. Italo Pardo discusses Italian rulers' breaches of the democratic contract binding them to safeguard two fundamental rights of citizenship: public safety and health. Naples, he argues, makes a graphically exemplary case of the toxic ramifications of three concurring obnoxious processes. They are: bad legislation has allowed a sneaky privatization of the public health service that compounds the heavy demands on the inadequate and understaffed public health system, raising serious challenges to key aspects — medical, moral and ethical — of the Hippocratic Oath; the personal and public health hazards generated by bad governance; economic policies that protect the guaranteed who enjoy secure employment but punish the non-guaranteed who independently make their own living. As the legitimacy of the 'system', he concludes, becomes questioned, the casualties are trust and, ultimately, authority. Dolores Koenig and Tiéman Diarra focus on the legitimacy of practices in healthcare in the area of the Manantali dam in western Mali, where structural adjustment programmes have pushed privatization in the ineffective national healthcare system without improving health care. Further reforms put local healthcare in the hands of community health centres (CSCOMs) as the focal point of primary healthcare, in which user fees generate funds to cover operating costs. CSCOMs have become the backbone of rural and small-town healthcare. Although these centres have decreased dubious practices and brought transparency, they still suffer from performance legitimacy. Patients find it difficult to pay costs, which affects the ability of the centres to pay operating costs, much less improve equipment and structures. At the same time, they also use traditional herbal treatments and the private health centre funded by the dam's power company. Linking to important aspects discussed by Prato, Sarfati, Varelaki, and Arnold, the Mantanali ethnography brings out the impact of the absence of adequate infrastructure and well-qualified personnel both on the provision of healthcare services and on people's choices.

The problem of inadequate structures and privatization practices is at the centre of Falia Varelaki's ethnographic research conducted in a Greek anti-cancer public hospital. She explores the field of therapeutic choice in the context of economic crisis in Greece, whereby cancer patients find themselves at the intersection of biomedicine and alternative medicine. Liora Sarfati recognizes that people seek traditional healers in many cases of chronic illness, mental issues, or terminal conditions that modern medicine cannot solve. However, reminiscent in a way of Prato's analysis of the re-discovered 'holistic' approach in certain medical fields, Sarfati notes that people may use both spiritual healing and biomedicine. Looking at the relationship between healers and patients in the hypermodern cultures of South Korea and Israel, she suggests that the tensions relate to institutional concerns and health issues than to the religious-supernatural aspects of the treatment. As discussed in Arnold's essay, the relationship between biomedicine and alternative and complementary therapies appears to be now at the centre of the search for 'cures' among patients suffering from Long Haul Covid. Having briefly outlined the state of healthcare in the US, Judy Arnold notes that the poverty of opportunity in the American Health Care System was exposed at its worst during the pandemic, which very nearly broke the American Health Care System. She argues that the experiences of Americans who sought health care and those who find themselves still sick from the effects of the virus raise key questions of legitimacy that need attention. This problematic resonates with Talbot Rogers' controversial findings among selected informants as to whether healthcare is or should be a right. There is one exception among G7 countries, he notes, as in the United States there is no universal coverage. Spyridakis raises similar points in his examination of the complex issues regarding people with disabilities in Greece. He reflects on the key fact that people with disabilities have health needs like every other citizen and require the same general health services as persons without disabilities, from promotion, prevention and treatment, to rehabilitation and palliative care. Even considering that, on average, due to the higher vulnerability to health, people with disabilities are likely to require and use health services more than those without disabilities, their unmet healthcare needs raise key issues of legitimacy that are at the core of good governance. Central in Spyridakis' analysis is what he calls the role of a 'medical-industrial complex' based on profit, which resonates strongly with Koenig and Diarra's, Pardo's, Prato's and Varelaki's analyses of the distortions brought by privatization into healthcare.

The legitimacy of care and the polluting effect of political interference comes across vividly in Ebru Kayaalp Jurich's examination of the conflicting ideas of legitimacy around the Covid-19 vaccine in Turkey. Ethnographic knowledge from Istanbul raises questions on whether the CoronaVac vaccine chosen by the authorities enjoy legitimation among the Turkish people, pointing to a complex relationship between trust, efficiency and legitimacy. Subhadra M. Channa's discussion links strongly to those by Kayaalp Jurich, Koenig and Diarra, Pardo, and Varelaki as she draws on her Delhi ethnography, including during the pandemic crisis from March 2020 to the present, to illustrate key areas of theoretical concern, such as legitimacy, populism and democracy and the troubled relationship between them. Most interesting, the inadequacies discussed by Channa in the Indian context parallel significant aspects of the iniquities of the US system highlighted by Arnold and Rogers and underscored by Nugent.

The gap between rulers and the ruled and its complex ramifications in terms of legitimacy, of policy, of action, of the authority to rule are central themes in the essays by Mollica and by Armstrong and Rosbrook-Thompson, who focus respectively on situations of ongoing geopolitical conflict and the application of matrix algorithms to 'predictive profiling' as a formula for the prevention, and by extension 'cure', of perceived social problems. Marcello Mollica's Lebanese study sheds light on the dichotomy at the National consociational level and at the level of local governance in the political management of public health at times of escalated crises. He examines the multi-level governance of public health in the context of three dramatic events that enhanced inter- and infra-confessional socio-political tension: the Hezbollah-Israeli War of 2006; the Covid-19 pandemic; and the explosion that ravaged Beirut on 4 August 2020. Gary Armstrong and James Rosbrook-Thompson examine through the lens of legitimacy the UK government's adoption of a public health approach to reducing levels of urban violence. They explore to what extent this is received as legitimate 'on the ground', arguing that it privileges a certain view of health and a skewed framing of the gang issue that engenders an inaccurate diagnosis of the problem. Their argument on the fallacy of algorithmic-based formulas for problem solving mirrors Prato's suggestion that healthcare cannot be reduced to a series of bureaucratic protocols and ambiguously constructed statistic indexes of 'efficiency' and 'resilience'. Ultimately, Armstrong and Rosbrook-Thompson's analysis point to an asymmetry between perceptions of legitimacy 'from above' and 'from below', when it comes to the epidemiological framing of urban violence.

The debate ends with an essay by David Nugent, who, on the strength of his anthropological knowledge, casts a keen eye on dramatic, and highly problematic, events in the US that have undermined citizens' trust in the authorities across the board to reflect on the essays offered in this Special Issue. His cogitations bring out comparative insights into the crisis of legitimacy which stimulate significant developments in this critical field of social theory.

As a whole, this Special Issue brings out the epistemological significance of charting new theoretical directions on 'legitimacy' and 'legitimation' that help us to grapple with the import and ramifications of world-wide discontent with how the dominant élite manage power, especially — though of course not only — in this absolutely critical field.

The future for this topic looks very promising. The synthetised studies given here, and the forthcoming extended publications (Pardo and Prato eds 2023), will hopefully stimulate further debate and new initiatives, including dissemination of the findings to a wider academic and non-academic audience.

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Healthcare Ethics in Urban Europe: Between Charity and National Welfare

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Charity and the 'Common Good'

Contemporary historians provocatively trace the origin of the welfare state to the role of hospitals in medieval society (Garbellotti 2013). In medieval Europe, the Christian charity ethos stimulated the establishment of hospitals as places of 'hospitality' to assist pilgrims and the urban poor — *pauperes et inopes*. By the late-Middle Ages, rich merchants were increasingly investing in these religiously-run institutions or in the creation of new 'lay' hospitals. Their philanthropy was in part stimulated by the effects of the emerging market economy on cities. On the one hand, philanthropic donations represented a form of wealth redistribution, stemming both from a religiously-inspired charity and a sense of civic duty. On the other hand, as municipal governments began to recognise the benefits of hospitals to the 'common good', wealthy citizens were encouraged by the ensuing tax incentives for donations in this field (Cipolla 1997). Private philanthropism and the urban administrative approach were inspired by a rediscovery of Aristotle's work — and his view of the city-*polis* as a 'political community that bridges the gap between the private sphere (the household economy) and the public sphere (the common good)' (Prato 2017: 56) — and the idea of *caritas* intended both as individual spiritual choice and as public instrument of assistance.[1] Late-medieval hospitals embodied a new relationship between political-administrative powers, market economy and citizens. Hospitals gradually acquired diversified social purposes, providing free services mainly, but not exclusively, in medical care and spiritual and moral support against suffering.

The above-described conception of hospitals as a 'holistic' healing environment — one that cared for a person's body, mind and spirit — has gradually moved towards the institutionalisation of hospitals as specialised 'bio-medical facilities' and, in line with the principles of twentieth-century neoliberalism, hospitals have been reduced to 'companies' where budget is a priority and medical performance is periodically audited and ranked. Parallel to this, faced with financial strains and higher public expectations, the role of state government has changed, too, to one of broker between people and private service providers. The UK and Italy are often singled out among those 'advanced' countries that are implementing such a shift, leading to the increasing marketization of the health system.[2]

Interestingly, in his book *Medical Nemesis* (1976), the philosopher Ivan Illich describes how, in the twentieth century, medicine has abandoned the 'holistic' approach and has been

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[1] This idea of *caritas* is famously represented in Lorenzetti's allegory of 'good government'. See also Pardo 2022: 16.

[2] Pardo (2022) on Italy and Spyridakis (2022) on Greece address similar questions in their respective essays.

reduced to the application of a series of protocols for the cure of specific symptoms. Such an approach now pervades all healthcare sectors; from the work of family doctors to the services provided by public medical institutions. The relationship between doctor and patient is regulated like a contract between an 'operator' and a 'customer'. In order to 'promote' the quality and efficiency of the service, doctors are expected to perform their 'technical duty' in line with the audit regime, which restricts their attention to patients.

Healthcare: From National Welfare to Devolved Services

Since the end of World War II, a key aspect of welfare policies in Italy and the UK has been the provision of 'free' healthcare and the protection of public health as a 'duty' towards its citizens. In Italy, the Italian Constitution and Regional Statutes pledge to fulfil such a duty. In the UK, the long tradition of welfare policies is embodied in various legislative acts.

Health, intended as a state of 'complete well-being', is also at the centre of international attention as one of the global 'sustainability goals'. Accordingly, national healthcare performances are periodically assessed and ranked in international reports that evaluate the effectiveness, accessibility and resilience of a country's healthcare system.[3] These report use data on: (i) the health status of the population (meaning, the life expectancy at birth); (ii) risk factors (such as smoking, drinking and obesity); (iii) health spending per capita. However, while the overall ranking seems to provide a positive image, the unpacked data reveal a different picture. Tellingly, *The Lancet* (2018) points to important limitations of the way in which these performance and quality indexes are constructed, stressing that they do not 'account for all potential factors related to health-care access and quality' (2018: 2259), including 'catastrophic health spending', insurance/private coverage and 'social determinants' (ibid.) of health, including discrepancies by socioeconomic status and across regions.

The 2019 OECD report ranks Italy and the UK among the best healthcare systems worldwide (OECD 2019).[4] In reality, these two countries have experienced serious drawbacks, especially due to an accelerated move towards the 'marketization' of healthcare. An outline of key legislative changes will help to put this situation into context.

The Italian national health service (Servizio Sanitario Nazionale, henceforth SSN) is fraught with serious limitations, due to frequent legislative changes on healthcare, cumbersome bureaucratic and administrative procedures, regional disparities and the financial burden placed on citizens though the imposition of out-of-pocket payments. Significantly, in Italy, public health spending is lower than the EU average (9.8%); most important, only 6.5% (about three-quarters) of the reported 8.8% of the Italian health spending is publicly funded, the rest is paid by the citizens through the so-called '*ticket*'.[5] Major

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[3] Koening and Diarra (2022) analyse these issues in relation to health institutions in Mali.

[4] A new 2021 report, to be published in 2022, will take into account the impact of the Covid-pandemic.

[5] Out-of-pocket payments on drugs prescriptions were introduced in 1982. The new *ticket* introduced in 1989 (d.lgs 23/03/1989) was presented as a form of partial cost-sharing — a citizen's duty — and a

legislative changes between 1991 and 1993 have extended this 'co-payment' to practically all health services and introduced a tripartite classification of drugs — specifically, Class-A drugs available on payment of a fixed ticket on the prescription; Class-B drugs, available on payment of 50% of their cost; Class-C drugs to be fully paid by the patient. In 1999, several paediatric antibiotics and life-saving drugs for chronic illnesses were re-classified as Class-B and Class-C drugs.

Another key aspect is that nowadays the SSN is territorially-based, often allowing for grey areas in the distributions of responsibilities between the State and Regional Administrations — this has critically emerged during the recent Covid-19 pandemic. Significant steps in this direction were introduced by the legislative decrees of the 1990s giving more power to the Regions,[6] which became increasingly responsible for the collection of *tickets* and the administration of the newly-established Local Healthcare Units (Unità Sanitarie Locali, henceforth USL); Regions also had the power to increase the *ticket* at their discretion, including the *ticket* on drug prescriptions.[7] The 1999 Bindi legislation strengthened the power of Regions and introduced a corporative approach in health planning and administration; thus the USL became Local Healthcare Corporations (Aziende Sanitarie Locali, henceforth ASL), in practice transforming healthcare services into 'commodities' and the patients into 'consumers'.[8] In 2001, the Reform of Chapter V of the Italian Constitution (Constitutional Law n.3, 18-10-2001) delivered the final blow. This reform entrusted the 'protection of citizens′ health' to Regions and autonomous Provinces; thus, critics say, leading to 21 different healthcare systems. A month later, a new Prime Ministerial Decree (DPCM 29-11-2001) introduced the bureaucratic division of the so-called 'Essential Levels of Assistance' (Livelli Essenziali di Assistenza, henceforth LEA) into three main areas: (i) public health and collective health assistance; (ii) territorial services (for example, family doctor, pharmacy/chemist, home services for the elderly and seriously ill, and so on); (iii) hospital services. Subsequent legislative updates, justified in terms of efficiency and resilience, added further complication, not necessarily easing people's access to healthcare; exemplary are a new agreement between Sate and Regions in 2006 for the development of 'Complex Unities of Primary Care' (UCCP), the Monti government's health reform (Law-8-novemebr-2012-n.189), the DM 2-aprile-2015-n.70, leading to the closure of local hospitals, including those that had been established with philanthropic bequest (Prato 2023), the 2017 DCPM that increased the financial burden on the Regions. Significantly, a new revision of the LEAs began in January 2021 (AGENAS 2021)

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deterrent against potential abuses of the services by the medical personnel. On abuses and various forms of 'moral' corruption among health personnel, see Pardo 2022.

[6] The capital letter is used when the word Region refers to the regional administration.

[7] The same test, or drug may have a different cost in different regions. Between 2009 and 2017, the *ticket* increased by an average of 2.5%, raising citizens' contribution to health spending to 23.5%.

[8] In 2000, the National Health Fund was eventually abolished (d.lgs 18-02-2000, n. 56), transferring almost all responsibility for health spending to the Regions.

as a consequence of a buck-passing 'debate' on responsibility between national government and regional administrations during the Covid-19 pandemic.

Ordinary Italians have given up trying to understand what they are actually entitled to. When they can afford to do so, they opt for private care. Most important, they see the 'legal imposition' of the *ticket* and certain legislative changes as a betrayal of the fundamental principles of *universality* and *equality* that had inspired the establishment of the SSN in 1978, raising serious issues of legitimacy and trust (Pardo 2000, Pardo and Prato 2019).[9] Furthermore, as I have mentioned earlier, the regionalisation of the system has increased disparities in healthcare provision and in life expectancy and personal wellbeing more generally. In particular, those who live in the southern regions often have to bear the extra cost of having to seek medical care in the northern regions; specifically, travel, lodging and living expenses for accompanying family members. A forthcoming work (Prato 2023) addresses these aspects drawing on ethnographic material collected in the Apulia and Tuscany regions.

The British National Health System (NHS) was established in 1948 as part of the post-WWII social reforms. It is an umbrella term for the public healthcare systems of the four UK 'nations' — England, Wales, Scotland and Northern Ireland. All four systems are funded out of general taxation and share the principle that healthcare should be comprehensive, free and universal. Since 1999, healthcare has become a devolved responsibility, meaning that each nation's NHS operates independently; it is regulated by, and accountable to the relevant government. [10] Thus, the way in which services are organised and paid for have diverged; each nation has its own planning and monitoring frameworks and its own public health agencies, resulting in differences across some policy areas, as it happened during the Covid-19. However, international reports tend to make a joint evaluation of the healthcare profile of the UK, pointing out that the four systems face similar challenges and often adopt similar solutions (OECD 2019), especially in addressing waiting times and the shortage of doctors, nurses and care workers. Generally, health spending across the UK is higher than the EU average and is said to deliver good health services.

Having done field-research in Southeast England, I focus on the English NHS. Like the Italian counterpart, the organisation of NHS-England (from now on, simply NHS) has

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[9] Before 1978, healthcare services were provided by the employment-based *casse mutue/enti mutualistici* (mutual-aid funds), which left out self-employed and unemployed. The *casse mutue*, established in 1958, followed the model of INAM (National Institute for Workers' Illness Assistance) introduced in 1943 (Law 11-01-1943, n. 38) as the crowning outcome of the 1926-1943 welfare reforms that established a stronger State control while compelling employers to provide medical assistance to their workers and their families. Differently from the previous 'mutual-aid societies' based on workers' voluntary subscription, INAM required compulsory contributions paid mainly by the employer and in small part by the workers.

[10] Scotland, Wales and North-Ireland are responsible for their respective Healthcare Service; NHS-England is regulated by the British government. With 80% of the UK population living in England, NHS-England is the largest.

changed overtime to address shortcomings and meet new needs. For example, prescription charges were abolished in 1965, but reintroduced three years later.[11] Throughout the 1970s and early-1980s, revisions of the original tripartite system (hospital services, primary care and community care) and of Local Health Authorities led to the establishment of Regional Health Authorities. Major reforms have occurred during the Thatcher and Blair governments (respectively, 1979-1990 and 1997-2007).

Key points of Margaret Thatcher's health reforms were the introduction in the 1980s of a 'modern' management process and the so-called 'internal market' in order to shape the structure and organization of health services. The 'internal market' model was outlined in two White Papers, 'Working for Patient' and 'Caring for People', which were opposed by the British Medical Association.[12] The model was revised, resulting in the 1990 'National Health Service and Community Care Act', whereby Health Authorities would stop running hospitals and instead would 'buy' care from their own or other authorities' hospitals. The 'providers' of the services were organised as 'NHS Trusts'.[13] Critics have argued that, while aimed at encouraging efficiency, the ensuing competition also increased local differences.

On becoming Prime Minister in 1997, Tony Blair promised to replace the 'internal market' with 'integrated care' that would combine 'efficiency and quality'. However, in his second term, he strengthened the 'internal market' as part of a modernising process that would increase standards, expand patients' choice and contain government expenditure. He also encouraged outsourcing of medical services and support to the private sector. Devolution (see footnote 10) increased differences between healthcare services across the UK.

Private sector involvement in the NHS intensified with the 'Health and Social Care Act 2012', provoking mass demonstration led by health workers. That year, the Department of Health published *The NHS Constitution for England* (DHSC 2012), which outlines the NHS commitments to patients and staff, and the reciprocal responsibilities between public, patients and staff 'to ensure that the NHS operates fairly and effectively'. It also sets out the government's commitment to produce up-to-date statements on NHS accountability on their decision-making.

In 2018, the British Government announced that NHS-England would receive a 3.4% increment in funding every year until 2024. This raised concern that funding would be used

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[11] Prescription charges are paid by almost all adults aged 16-60.

[12] In British politics, a White Paper is a 'tool of participatory democracy' that performs the dual role of presenting government policies while at the same time inviting opinions upon them, and can therefore be amended.

[13] In the English Common Law, a Trust is a legal arrangement for managing assets; it indicates a legal relationship in which the legal title to the assets is entrusted to a person or legal entity with a fiduciary (that is, in trust) to hold and use it for another's benefit. NHS Trusts are legally independent Public Benefit Corporations that remain fully part of the NHS and are monitored by an independent organisation — called Monitor — which is directly accountable to Parliament.

to pay NHS debt rather than to improve patient care — two-thirds of hospitals were in deficit (SkyNews 2018).[14]

Interestingly, although reforms have often led to conflict between government and healthcare personnel, especially on the issue of outsourcing to the private sector, ordinary people claim to be proud of 'their NHS', saying say that, overall, the system meets their needs. Such positive attitude of the general public is in part explained with other aspects that are usually ignored in the official 'quality reports', but guarantee the NHS's efficiency and resilience; in particular, the role of charities and voluntary work, which I analyse in the aforementioned forthcoming work (Prato 2023).

How the Pandemic Exposed the Urgent Need for Change

In an earlier publication titled *Pandemic Ruptures* (Prato 2020b), I reflected on the immediate impact of the ongoing Covid pandemic on people's social and personal life. There, I also pondered what course of action governments would take to prevent the NHS from being overwhelmed again (Prato 2020b:108). The Covid-19 emergency has shown that the unpreparedness of the Italian and British health services was mostly due to increasing privatization. It also brought out that healthcare cannot be reduced to a series of bureaucratic protocols and statistical indexes[15] on ambiguously measured 'efficiency' and 'resilience'. The pandemic emergency has once more exposed the dilemma of State intervention in the regulation of such an important public service and the protection of public health. As I argued elsewhere, during the pandemic, governments appeared 'to be using the "state of emergency" as a political strategy to establish new forms of control, while skirting their responsibilities' (Prato 2020a: 8), raising questions on the legitimacy of their action (Pardo 2000, Pardo and Prato 2019). In this scenario, existing inequalities have been exacerbated and new injustice generated (Prato 2020a; Pardo and Prato 2021). Meanwhile, doctors and health personnel have been hailed as heroes. Indeed, they went above and beyond their bureaucratically-demanded duties, working tirelessly and daily risking their lives (Prato 2020a). Their heroism has been supported by people's volunteering and charities' work, in recognition of the difficult situation in which they had to operate. Sadly, however, the governments' *verbal* glorification of such personnel is overshadowing the dramatic reality of the public health services. While health security has become an essential part of international political strategies, such glorification is misdirecting governments' attention from the urgent need for changes; meanwhile dissatisfaction and disillusion among doctors and nurses as well as patients rise. In Italy and the UK, thousands of doctors abandon the public health service each year.

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[14] In early-2022, the UK government announced an increase of 1.25% in National Insurance Contributions (NICs), to be spent on the NHS, health and social care. NICs are social security contributions paid by employers and employees, and self-employed.

[15] Armstrong and Rosbrook-Thompson (2022) address similar issues in their analysis of the public health approach to urban violence in the UK.

Conclusion: The beginning in the end?

Across society there is a growing demand for a better health system. Promises made during the pandemic remain unfulfilled. Future historians might describe the ongoing pandemic as a time of generalized 'crisis' — in economics, politics, international relations — which, unsurprisingly, generates social turbulence (see Nugent 2022). We should not forget, however, that 'crisis' does not simply carry the meaning of 'danger', but it also signifies 'to discern', 'to judge', 'to choose'. It compels people to make decisions and, thus, provides an opportunity for change.

As I mentioned earlier, the pandemic 'ruptures' only exacerbated an already critical situation, which national governments have tried to remedy through several legislative changes. In the UK, a greater involvement of the local community and of patients has been proposed, building on the tradition of volunteering, philanthropism and charities' work. In Italy, relatively new schemes, such as the 'Supplementary health care funds for businesses' and the so-called 'Health Cooperatives', are promoted as a reliable enterprise model for health and wellbeing (Prato 2023). However, the legitimacy of some initiatives is questioned both by the health personnel and by the patients. This reminds us that legitimacy is not automatically granted to abstract legislations and to actions that strictly abide by bureaucratic regulations. In contrast, the legitimacy of the system is questioned when bureaucratic regulations, instead of facilitating common welfare, generate inequalities and increasingly jeopardise people's physical, emotional and psychological wellbeing.

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Illegitimate Rule Harms Italians' Health and Safety

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Doing Good Government has always been a boring, sometimes vexing nuisance for irresponsible, inefficient or 'simply' dishonest élite.

Thinking of Good Government in non-totalitarian regimes, one thinks of the principles of Equity, Justice and Magnanimity that distinguish Ambrogio Lorenzetti's representation of Good Government in the Palazzo Pubblico, Siena (1338-1339).[1] In a democracy, these principles underscore a *sine qua non* of Good Governance: rulers' duty to safeguard the rights of citizenship. Two fundamental such rights are healthcare and public safety. It follows that, absolutely critical to the democratic covenant between rulers and the ruled (Stankiewicz 1980, Prato 2019, Pardo 2021), the management of both needs to be recognized as legitimate in the broader society. This is a bedrock concept in the theoretical contention that the authority of leaders is inevitably based on credibility, management of responsibility and reciprocal trust with citizens. In Italy, as in other Western countries, misgovernance and criminal and non-criminal corruption in public and professional life (Pardo 2018) deeply undermine this *fundamental* of associated life in a context where citizenship rights are Constitutionally stated, though not always protected in reality.

This brief article precedes a full-length essay to be published in an edited volume (Pardo and Prato 2023). The analysis heeds the key concept in the anthropological reflection on legitimacy (Pardo 2000, Björklund Larsen 2010, Pardo and Prato 2019) that not all that is legal is received as legitimate in the broader society and that, there, not all the strictly illegal is necessarily viewed as illegitimate. Given the limited space at my disposal, at the appropriate places I shall refer the reader to separate works for more information and analysis on these issues.

Naples' urban reality graphically exemplifies the ramifications of bad legislation that has allowed a sneaky, ever-growing privatization of the public health service, the personal and public health hazards generated by bad governance and the weight of unfair, punitive policies on ordinary people's lives. The ethnography collected through long-term traditional anthropological fieldwork plus a wealth of informants' reports collected from a distance throughout the pandemic — a precious by-product of well-established relationships that go back a long time —[2] testifies to the tyranny (Arendt 1951) of the structural inequality that historically undermines local society; a tyranny now dramatically evidenced by the impact of Covid-19.

Empirical knowledge and the theoretical insights offered by anthropological reflection help us to understand the unconscionable tension between *de jure* and *de facto* legitimacy that qualifies

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[1] The front cover of *Citizenship and the Legitimacy of Governance* (Pardo and Prato 2010) shows significant details of Lorenzetti's opposing frescoes of Good Government and Bad Government.

[2] For accounts of long-term anthropological field research in Naples and its Region, see Pardo (1996 and 2017). A recent article deals with the methodological issues that have arisen during the Covid-19 pandemic (Pardo 2020b).

ordinary Neapolitans' access to healthcare, their right to public health and safety and growing precariousness in their lives. In a national scenario dominated by the unspoken but pervasive con that the tax-paying citizen is in debt with the state, they are dealt a mighty triple blow that effectively turns them, as they say, into '*figli di un Dio minore*' (children of a lesser god), citizens whose life is *made* pervasively hazardous and precarious. They are saddled with a health service that, increasingly, is public in name only. They are forced to live in a filthy and hazardous public domain. They are subjected to discriminative policies that disadvantage large, vulnerable proportions of the population. Let us look briefly at these three blows.

1) *A* Public *Health Service?*

In Italy, healthcare has been gradually turned from a right to a commodity. Since the early 1990, this progression has ridden on the back of the so-called *intra moenia* scheme, whereby medical personnel are legally allowed to exercise privately while publicly employed in the aptly, if ominously, named Aziende Sanitarie Locali; literally, Local Healthcare Companies, generally known by the acronym ASL. The ASLs are part-funded by the central government and are managed by the Regional authorities, which, as Prato notes (2022), explains significant variations (in technical equipment, personnel, performance, cost to the patient, and so on) across the 21 Regions. Flying in the face of the Constitutional principle that healthcare is a citizen's right (one's taxes pay, of course among other things, for one's healthcare), an ever-expanding proportion of medical and pharmaceutical services is accessible only by private purchase, and access to the rest involves varying amounts of payment. Over the years, these legal yet illegitimate dynamics have been paralleled by cuts in public funding to the tune of 37 billion Euros (Fondazione Gimbe 2019).

The impact of the foregoing is felt more in some Regions, like Naples', where the everyday reality of the inadequate and understaffed public health system raises serious challenges to key aspects — medical, moral and ethical — of the Hippocratic Oath. As a social anthropologist doing field research since the early 1980s, I have recorded how the actions of some in the medical profession contribute to the deterioration of public healthcare. I have observed the conflict between the dedication and professionalism of many doctors, nurses and health administrators and the corruption — moral, criminal or both — of some. While many medical staff scrupulously abide by what can be appropriately described as the sacrality of their science and conscience obligation, others do not. A significant minority — some well-qualified but morally corrupt, some holding bogus qualifications obtained through corruption (Beneduce 2021) — betray this fundamental principle, as they generally stay within the strictly-defined boundaries of the Law but practice what their patients resent as *de facto* abuses of power, pursuit of private interest in public office and monetary and career greed. These unscrupulous — and well-networked (Beneduce 2019) — medics, trade unionists, contractors and agents of pharmaceutical companies act, often jointly, with little or no concern for the health (even the life) of the patient. Not always for good reason, some refer their public health-service patients to their private practice, or to private specialists, or to private test laboratories (in each case, tax-avoiding cash payments are requested), and so on. Once these professionals sell their public office and professional ethics, their profitable contacts expand, as do their lucrative contracts with private medical establishments and their favour-credit among their networks.

These actions may or may not fall outside the strictly defined boundaries of the law. This matters not to my informants. What matters to them is that the corruption of the best is the worst, a rot long known to Western wisdom and well encapsulated by the ancient phrase, *corruptio optimi pessima*. What matters to ordinary men and women are the practical ramifications of the (mostly legalised) corrupt metamorphosis of the right to healthcare into a ‘commodity’. What matters to them is that, adding scorn to injury, all-too-often — and usually, preposterously, publicly — this ‘commodity’ becomes a privilege, as they see the powerful and the well-connected who systematically benefit from preferential treatment. On the strength of legalistic technicisms that remain obscure to the non-specialist, and totally incomprehensible to ordinary citizens, they mostly do so without committing crimes but betraying, nonetheless, basic principles of legitimacy in the spirit and in the letter.[3] What matters to our analysis is that the insidious, malignant impact of these actions is invariably received at the grassroots as a betrayal of the ‘first do no harm’ principle, a despicable corruption that *hits one when one is at one’s most vulnerable*.

Interestingly, these efforts to turn patients into customers, or clients, or supplicants do not always appear to have the intended results. Stubbornly resisting pressure to make them subaltern to some ‘superior powers’, the ordinary Neapolitans whom I have met over the years have developed varied and complex ways to deal with this and most other distortions of associated life. As I have explained elsewhere in detail (Pardo 1996: Ch. 6 and 2017), inspired by their fundamental will ‘not to be subject to anyone’,[4] many have built multiple contacts and generalized relations of (often delayed) exchange. When in need, they use more than one contact, usually with good *and* relatively not-too-expensive results.

2) *A Filthy and Hazardous Public Domain*

The developments that I have outlined occur in a context where uncollected rubbish continues to jeopardise local public health[5] in lethal combination with the injuries and deaths caused by badly maintained public property — overflowing sewage; falling trees; broken or uneven walkways (*Il Mattino* 2019); large and deep potholes; pieces of public buildings that fall on pedestrians (*La Repubblica Napoli* 2019); and so on.

These hazards now include a ‘rubbish trade’, whereby illegal immigrants peddle objects scavenged from dumpsters and displayed for sale on rugs thrown on the pavement; a practice on which the authorities appear persistently inclined to turn a blind eye. In spite of citizens’ repeated protests and widely reported appeals to the authorities (Garau 2020), this practice has expanded across the city centre (Folle 2021).[6]

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[3] Exemplifying a notoriously widespread behavior among the privileged (Bechis 2021), a well-known journalist in his forties managed to get vaccinated before his compatriots who were elderly or at risk, yet *technically* did not commit a crime (Adnkronos 2021).

[4] They say: *Nun voglio sta suggett’ a nisciun’*.

[5] This continuing problem (Corriere del Mezzogiorno 2022) has become entrenched since the early 1990s. Some of those responsible are under criminal investigation (Beneduce 2020).

[6] For more on this, see Pardo (2020a).

This dangerous setup is magnified by the practice of shallow-burying household, industrial and hazardous waste in dumping sites (Beccaloni et al. 2020). Over the years, pulmonary disease, cancer and death have multiplied exponentially (Senior and Mazza 2004, Martuzzi et al. 2009, Beccaloni et al. 2020).

In short, for over 30 years, local authorities have mismanaged public property and what takes place there. That such mismanagement should have continued during the pandemic has raised widespread anger among citizens. A local friend's experience at the height of the pandemic is exemplary:

> 'We can only take care, try to stay safe and hope for the best, you know. The reality is: A politician has a temperature? Test! Someone famous has a temperature? Test! One of us has a temperature? Call emergency and pray! My brother has all the symptoms of this virus. He has not been tested. One doctor talked to him on the 'phone with no results. Yesterday I drove him to the hospital. Couldn't get in. A sign on the door said "We are closed due to COVID-19"! Meanwhile, the government floods us with injunctions that contradict each other. What a deadly mess!'

3) *Discriminative Policies that Disadvantage Many*

As authoritatively stated by Gian Carlo Blangiardo, the President of ISTAT (*Il Tempo*, 24 May 2021), 'in 2020 the number of people below the poverty threshold reached unprecedent levels'. Meeting Prato's discussion (2020) of new inequalities, he points out that the increase in poverty is explained by the loss of jobs and income, especially among the self-employed and the micro and small entrepreneurs.

Earlier, I mentioned the inequality between the privileged and 'the others'. Let us now dwell briefly on 'the others' to consider the inequality between the secured and the unsecured and its impact especially in times of crisis. The historical bias of a certain political ideology against the self-employed and micro and small entrepreneurs is known and widely discussed in the literature (Pardo 1996: Ch.2; 2017: 39-43; 2021). This bias has played a key role in discriminating between the non-guaranteed, who are traditionally forced to fence for themselves, and the guaranteed, who enjoy secure, trade-union-protected employment mostly in the public overstaffed and historically clientelism-ridden sector. In this environment marked by extraordinarily high formal unemployment (Banca d'Italia 2020), most informants are (by choice or more often *perforce*) self-employed (Pardo 1996: Ch. 2; 2017). They have developed excellent entrepreneurial abilities, unfortunately mostly limited by the context to the micro and small level.

In recent decades, 'those in command', as my informants contemptuously say, have proved stubbornly allergic to a fundamental democratic rule: power must be determined by the electorate and its exercise must take place under a regime of responsibility within publicly recognizable limits. Rulers who are mostly unelected are *appointed* by political bosses who manage State powers to serve their and their gang's interests. Recently, they have used the pandemic as a convenient trojan horse to grab extraordinary powers and impose incredibly unfair policies, while continuing to exercise power Italian style; ruling, that is, without being elected and staying in power despite losing the elections.[7] Lockdowns (inevitably impeding business) and the exacerbation of bureaucratic and fiscal weight have brought to bear the aforementioned political bias, amplifying throughout the country the inequality between the guaranteed and the non-guaranteed, with particularly devastating effects in urban environments like that we are dealing with.

During the pandemic, none of my 'non-guaranteed' Neapolitan friends received help or assistance, monetary or otherwise, from the local, regional or national government. Many were driven out of business; others, who worked for small entrepreneurs, lost their jobs. As always, these non-guaranteed could count only on themselves; the 'luckier' among them, could rely on limited help from their kin. Local stall-keepers' experience typifies the plight of precarious workers' struggle to survive. One friend remarked:

> 'Market's shut. I can't work. No one is helping. Savings are dwindling. My children and wife are barely coping. Nerves are frayed. The neighbourhood is dirtier than ever. Yeah, we'll be all right indeed!'.

As another put it,

> 'we've been forced to eat the few savings from a lifetime of working without a parachute. Now I and mine're truly in the shit, as we have almost nothing left to fall upon. If, God forbid, one of us should fall seriously ill as my little daughter did a few years ago, we'd have to borrow from loan-sharks. We have no guarantees, you know; so, banks won't even look at us.'[8]

The severe impact of this third blow has egregiously complemented the punishing job done by the seriously crippled health 'service' and the misgovernance of the public domain. The precarious are more precarious, or dead. The guaranteed have kept their jobs and financial security; the well-connected have thrived; the wealthy have become wealthier.

Closing Remarks

At risk of labouring a point that I believe to be fundamental, let me remind the reader that, by definition, misgovernance breaches the democratic contract with citizenship. When it affects people where it hurts most, I argue, the legitimacy of the 'system' becomes dangerously questioned; the casualties are trust and, ultimately, authority. The Naples ethnography graphically exemplifies this progression in a country that has manifestly become a test case for social and political consequences of the eroded legitimacy of the system which, until relatively recently too dire to contemplate, are now unescapably real.

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[7] For an anthropological analysis of this practice, see Pardo 2021.

[8] I have discussed local experiences during the pandemic (Pardo 2020b). The forthcoming full-length chapter cited earlier (Pardo 2022) offers ethnographic evidence on the plight of these Neapolitans.

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Local Perspectives on the Legitimacy of Health Institutions in Manantali, Mali

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Pardo and Prato (2019: 9) have discussed the importance of understanding the everyday practices around government legitimacy and the processes that contribute to legitimation and delegitimation. Reciprocal trust is crucial in creating credibility, as citizens constantly assess the actions and motivations of government actors (Pardo and Prato 2019: 11). This piece focuses on the legitimacy of everyday practices in health care in the area of the Manantali dam in Western Mali. It focuses on two aspects: 1) performance legitimacy, the ability to offer effective and quality services, and 2) process legitimacy, agreed rules of procedure for acceptable action (OECD 2010: 23).

Legitimacy and Health Care in Mali

When Mali became independent in 1960, its socialist government put in place a system of public hospitals and practitioners meant to serve all its people. For about ten years, the new government benefited from international assistance (Mariko 1993: 247), but afterwards, contributions to the national budget for health steadily decreased, and the state was unable to fund adequately all levels of the national health system (Coulibaly and Diarra 1993). Most small town and rural health centres lacked personnel, equipment and drugs. In this context, medical personnel often indulged in dishonest and sometimes harmful behaviour along the lines described by Pardo (2004, 2022) and Prato (2022). Coulibaly and Diarra (1993: 234) noted corruption, theft and other illegal practices. Agents often asked for money for care that should have been free or charged for extras beyond posted fees (Tinta 1993: 223). Physicians and other health professionals, then universally employed by the state, also illegitimately saw private patients. In 1986, patients spent an estimated US$ 1.597 million on private clandestine medicine (Coulibaly and Diarra 1993: 243). Through the 1980s, Mali's national health care system, with little trust between providers and users, lacked both performance and process legitimacy.

Then, structural adjustment programs pushed the Malian state to disengage from health service provision. Private medical practice was legalized in 1983. The government monopoly on the import and distribution of pharmaceuticals was ended in 1991. These changes did not directly improve health services, so policy makers began to look at other options, including cost recovery, health insurance, mutual insurance associations, and the use of generic drugs (Coulibaly and Diarra 1993: 240).

Since then, the key institution in the health care system has become the *Centre de Santé Communautaire* (CSCOM, Community Health Centre), in which user fees from patients generate funds to cover operating costs, including salaries. The idea was first piloted in a spontaneous neighbourhood in Mali's capital as an experiment that involved Tiéman Diarra as implementor and researcher. The first CSCOM was opened there in March 1989 (Diarra 2012). By 2001, there were 350 CSCOMs (Balique et al. 2001), by 2011, 1086 (Mali 2014: 20).

The formation of a CSCOM starts with the establishment of a community-based non-profit *Association de Santé Communautaire* (ASACO, Community Health Association), which first launches and then manages the CSCOM. Although private not-for-profit institutions, ASACOs and CSCOMs are under the supervision of the state, which verifies respect for four essential conditions: ASACO respect for democratic rules, legitimacy of the CSCOM director's authority and decisions, not-for-profit status, and accounting transparency (Balique et al. 2001: 38-9). As more communities wanted CSCOMs, the government established rules for their creation as an integral part of the national health system with different tiers of care. A convention of mutual assistance between the government and the ASACO-CSCOM jointly established the roles and obligations of the partners. Government funding to equip new CSCOMs and aid in recruiting personnel is available; some also get assistance from NGO programs.

The community-run ASACO has conferred transparency on CSCOM operations and is a key guarantee of their process legitimacy. In contrast, the performance legitimacy of CSCOMs is fragile. Many CSCOMs have insufficient income to sustain them (Konaté and Kanté 2005: 137). The number of visits may not cover costs (Balique et al. 2001), although sometimes the deficit is made up by drug sales (Konaté and Kanté 2005: 144-5). Nevertheless, residents sometimes complained that the supply of essential medications was not reliable (Konaté and Kanté 2005: 143). The financial problems were compounded by lack of qualified personnel, low use of service, inadequate infrastructure and equipment, and poor performance (Coulibaly et al. 2020: 2).

For advanced care, people usually move into the public system. Most prefectures in Mali have public referral hospitals; public hospitals in regional capitals treat more complex cases. The capital, Bamako, houses five public hospitals and government research institutes for public health, blood transfusions, child survival and sickle cell disease (Mali 2014: 19). Private options are also available, mostly in major cities.

These tiers of care build on the CSCOMs, now the-state recognized backbone of Mali's health system and the first level of contact for health services.

Health Care in Manantali in the Early 2000s

Although Manantali[1] is similar to many areas of rural Mali, it is different in one striking way. It is the site of a high dam, built in the mid-1980s to provide electricity and improve irrigation and navigation to the states of the OMVS (*Organisation pour la Mise en Valeur du Fleuve Sénégal*, Senegal River Basin Authority) at the time of dam construction: Mali, Mauritania and Senegal.[2] There has since been rapid change, including the construction of roads and new villages for the 8850 people displaced from the reservoir, most of whom now live downstream of the dam. The dam galvanized the growth of Manantali town, a small rural service centre with about 10,000 inhabitants in 2016. The area was also affected by significant national changes, not only structural adjustment, but also democratization, political decentralization, and

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[1] The term Manantali refers to the dam, the town, and the wider area.

[2] Since then, Guinea has joined the organization.

associated development initiatives from the early 1990s onward. With decentralization, the area created two communes, Bamafele and Diokeli, each with an elected council and mayor.

The town of Manantali occupies an anomalous position. As part of the commune of Bamafele, it comprises approximately half its population, while the other half is dispersed among 25 villages. However, the land upon which the town is located is owned by the OMVS, which continues to support some of its infrastructure, including a health centre. Although the town is large and wealthier than the villages, the commune political centre is the village of Bamafele.

The information here comes from a study funded by the US National Science Foundation (BCS-1560543) in 2016-19 to understand the effects of resettlement, with special attention to those displaced from the reservoir in the mid-1980s. The research team followed a sample of 137 households, 108 resettlers and 29 hosts. In each, up to four members were interviewed; not all households had people in each category. Relevant here, male heads and one older woman were asked their responses to household illness and what health centres they used. Younger men and women were asked how they tended to their health and whether and where they sought modern health care. Qualitative information was also collected on Manantali's health institutions.

Before the resettlement in the mid-1980s, the area health institutions suffered from performance and process illegitimacy. The administrative centre of Bamafele had a 'rudimentary' health post staffed by a senior nurse and midwife (USAID 1984 Annex 7.7: 10). There was virtually no equipment; rarely were drugs available. In an isolated area, people said that they had to walk up to three days to get to decent health facilities.

Now, as in most of Mali, the provision of modern medicine is based on CSCOMs. The commune of Bamafele has three. The first, in Bamafele, the commune centre, was established in 1998 as a transformation of an older health post built by the resettlement project. A second CSCOM was created in 2003 in Marena, on the other side of the Bafing river, to serve the villages there. A third CSCOM was opened in Manantali town in 2021. Unlike the village CSCOMs, this one promised stable running water and electricity; it hoped to provide an operating room, x-ray and ultrasound machine. Bamafele also supervised a satellite health post in an upstream village, to serve the minority who lived there. In contrast, the more rural commune of Diokeli, with about the same population as Bamafele, has only one CSCOM, in the commune centre. All the CSCOMs are formally linked to the government referral hospital in the prefecture, Bafoulabe.

Manantali town also includes a health centre owned and staffed by the OMVS, known to residents as the 'hospital' of Manantali. Originally built to serve construction managers and workers, it continues to function and is open to all. This health centre has a working x-ray, an oxygen treatment room and four hospital rooms, as well as consultation rooms and offices for doctors and nurses. The OMVS also runs a smaller dispensary, which focuses on prenatal, infant and child care, family planning, routine vaccinations, and malnutrition. Although the OMVS health centres send patients to government referral hospitals, they are not formally integrated into the Malian public health care system.

Health Care Options in Manantali

Manantali residents evaluated the legitimacy of their health care institutions using concrete criteria. People did not talk of dishonesty, favouritism, under-the-table payments or other evidence of process illegitimacy in the context of health care, although they often mentioned it in other domains. Therefore, this section focuses on performance legitimacy, as evaluated by availability, cost, effectiveness and quality of the health care institutions.

Available health care options included both traditional and modern medicine.[3] Both were practiced in Manantali. There were three traditional specialists in our sample; all claimed relatively successful practices. They treated mental illnesses, epilepsy, infertility, and diseases with supernatural causes. The sample also included a traditional bonesetter and several midwives. No one mentioned using traditional specialists in answer to the interview questions about provision of family health care. However, other information indicated that several people in the sample had been treated by them for mental illness and impotence.

By far, the most common use of traditional medicine was the home-based preparation of plants and leaves for teas or washing solutions. These medicines are based on gathered or cultivated plants, and their preparation is widely known and based on local knowledge passed down for generations. In answer to our questions about sources of health care, a substantial minority of women, both older and younger, and younger men said they used plant-based medicines exclusively. More commonly, all categories of individuals used both traditional medicines and the modern health system. Generally, they tried traditional medicines first, but if they did not work, they turned to modern health care, especially the CSCOM. Traditional health care, widely available, is often, but not always effective. In other words, it is legitimate but not for all health problems.

Although the majority of residents used modern medicine and the national health system, they had problems with its cost. Despite the fact that CSCOM fees are kept low, many people found it difficult to pay for consultations, treatment and medications. Although many brought ill family members to the CSCOM, about a quarter of household heads said that it was not easy to pay. They brought up the need to borrow money, to call upon migrant family members, to sell livestock, and to use savings. Some 18% of older women also brought up these problems, as well as the cost of transport to health centres.

Availability of both personnel and medicines at the CSCOMs was raised by some respondents. A few also had questions about quality of care. Several called into question the capability of the physician at Diokeli; more commonly, people complained that he was often absent. A few also complained about the absence of the physician at Marena. Several people also said that appropriate medications were not always available at the CSCOMs.

Both ASACOs and CSCOMs were aware of these problems in performance, but they did not always agree on what should be done and who should do it. CSCOM personnel presented lists of needs: unfilled positions, housing for the medical team, renovations to buildings and

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[3] Malians of all social classes throughout the country mix modern and traditional medicine. Although individuals may reject one domain or the other, the legitimacy of both sorts of medicine is generally accepted, in contrast to other places (e.g. Sarfati 2022).

equipment, improvements to the water supply, incinerators for medical waste, better transport for patients. Medical directors generally thought the ASACO boards could be more proactive and should manage their financial resources better. They also wanted ASACOs to find ‘partners’ who could aid with funds, particularly NGOs who might finance particular needs. In turn, ASACOs struggled to manage with restricted budgets, linked to the CSCOM income. Some said they faced difficulty in paying required salaries and the monthly electric bill and were not always up to date on employee insurance. Indeed, the Diokeli commune paid half the physician’s salary to relieve pressure on the ASACO. In general, there was little money for improvements. ASACOs confirmed that there were sometimes shortages of essential medications.

Despite the problems, patients generally trusted the CSCOMs. Many young women went for regular prenatal consultations; a significant number delivered their babies there. A few mentioned regular treatment for chronic diseases. This was a significant change from what their life had been before the resettlement. Yet the basic legitimacy of the CSCOMs, a consistent level of quality care at a reasonable price, is not assured, because their economic fragility affects their performance.

People did not question the legitimacy of the system as a whole as much as the individual CSCOMs, clinics and hospitals. Often, they did not go to the CSCOM in their commune or to the closest one. They also did not go consistently to the same site for primary health care. For example, in the commune of Bamafele, which includes the OMVS facilities in Manantali, interviewees were almost as likely to use OMVS facilities as the Bamafele CSCOM. Twelve heads and six older women said the household used the Bamafele CSCOM, while eight heads and seven older women said household members went to both Manantali and Bamafele. The pattern was similar in Marena, the area of Bamafele commune across the river. Nine heads and seven older women said the household primarily used Marena CSCOM, but 12 heads and eight older women said they used Manantali, usually along with Marena, but a few times Manantali only. The upstream villages, a part of Bamafele, rarely if ever used its CSCOM, which was far away. Rather they used other CSCOMs upstream; if they needed more advanced care, they often went to the referral hospital in Kita, a neighbouring prefecture.

In Diokeli, people made different choices. Slightly less than half of heads and slightly more than half of older women used mainly the Diokeli CSCOM. A significant minority used Bamafele. Others used both Diokeli and Bamafele CSCOMs; more than half of them also sent people to Manantali. A few used Diokeli and Manantali only. For advanced care, a number went not only to Bafoulabe, but mentioned using the regional hospital at Kayes or getting care in Bamako.

Many residents chose the OMVS health services at Manantali for at least some of their care. Although not an official referral hospital, it served as such for many households. They often clarified that when something was complicated, they went directly to Manantali. People also believed that a physician would be more reliably present in Manantali, and several mentioned that its pharmacy was cheaper.

In light of these choices, it is worth asking how the presence of a better equipped CSCOM at Manantali, opened after these data were collected, would affect how people evaluate their options. If this centre offers good quality and low prices, it may attract patients from existing CSCOMs. Those who already have problems facing costs may see their incomes further erode, making them more fragile.

Conclusion

The establishment of CSCOMs has done much to increase transparency, trust, and process legitimacy in health care at Manantali, but performance legitimacy remains fragile. The ASACOs that manage the CSCOMs often struggle to meet operating costs and find it even more difficult to maintain and upgrade equipment and locales. Thus, the viability of established CSCOMs may suffer as newer ones, better equipped with initial start-up funds, open. For example, the Diokeli CSCOM, already facing financial constraints and viewed as problematic by some patients, may lose even more clients. If the fall in income means that minimum services cannot be maintained, the commune could lose its only health centre. To be sure, patients could still use the abundant services in Bamafele, but this puts poorer patients at greater risk, as they are less likely to be able to afford transport there.

If the Malian government values the presence of universal basic health services, it needs to increase government support for CSCOMs in poorer areas to maintain performance legitimacy. For example, it should consider grants and funding for renewing equipment and structures and advanced training for personnel.

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Special Issue — Edited by Italo Pardo and Giuliana B. Prato
Healthcare and Public Health: Questions of Legitimacy

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Legality and Morality in Cancer Care-The Right to Choose: Constructing 'Otherness' in Medical Pluralism

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Introduction

Cancer, not as a disease but as an experience and as 'something that happens between people' (Livingston 2012: 6), is the third cause of death in Greece after ischaemic heart disease and cerebrovascular disease;[1] approximately 64,530 new cases were recorded in 2020. According to Jain Lochlann, 'in an ideal world, a cancer diagnosis would come with an explanation of cause and move on to successful treatment' (2013: 19). Reflecting on Lochlann's argument, I wonder, what does 'successful treatment' mean?

Cancer treatment, within the context of medical pluralism, includes the biomedical therapeutic pathway which consists of surgery, chemotherapy, radiotherapy, biological therapies, and hormone therapy, but also CAM (Complementary and Alternative Medicine) which includes mind-body therapies (meditation, biofeedback, hypnosis, yoga, Tai Chi, imagery, creative outlets), biologically based practices (vitamins and dietary supplements, botanicals, herbs and spices, special foods or diets), manipulative and body-based practices (massage, chiropractic therapy, reflexology) and biofield therapy (reiki, therapeutic touch).[2]

In Greece, it is illegal to practice medicine and perform treatments unless you are a certificated doctor. It is also illegal to sell and distribute medicines and pharmaceuticals which are not approved by the National Organization for Medicines. Biomedical treatment methods are the official forms of medical practice but many of the patients choose to combine them with complementary treatments in order to relief the side effects caused by the biomedical treatment. On the other hand, alternative medicine, as the 'other' of the modern biomedical system (Ross 2012: 2) exists outside of the Greek health care system. Alternative medicine is usually practiced by healers or doctors and there is no specific legislation on the use and the practice of it.

In Greek, the word *alternative* («εναλλακτικός») means (1) someone or something that may be interchanged or may be used instead of another, or (2) someone or something that challenges established forms and norms. As Ross notes, 'it is significant that alter means "other" in Latin […] and that the notion of alternative references the idea of choice, most commonly between mutually exclusive possibilities' (Ross 2012: 6). Patients who choose an alternative treatment method usually deny any biomedical treatment method.

The plurality of therapeutic options for cancer is impossible to be depicted numerically for the Greek context as there is no National Cancer Registry, hence, there are no data concerning cancer patients in Greece. That means that since there is no official record of people being diagnosed with any form of cancer, there is also no record for their therapeutic choice. Patients as medical consumers acquire 'an active role in becoming informed, making medical decisions, and

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[1] Eurostat, 2016. https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Causes_of_death_statistics , accessed 20 June 2021.

[2] National Cancer Institute U.S. https://www.cancer.gov/about-cancer/treatment/cam; accessed 20 June 2021.

determining the course of treatment and care' (Sulik and Eich-Krohm 2008: 7). In a social context where multiple treatment modalities are offered, patients can choose from the 'treatment pool' and follow the biomedical treatment process, an alternative treatment, or a combination of the two.

Here, I examine the conflicting relationship that seems to be raised within the context of medical pluralism. Drawing on material from the ethnographic research that I conducted in a public cancer hospital in Athens (Greece), I explore the context of therapeutic choice, the process of which is resulting into the emergence of discourses around morality, legality and trust (Pardo 2000). Additional interviews had to be made in circumstances of pandemic, thus they were conducted by phone, and they included patients who exclusively followed alternative treatment methods after their cancer diagnosis. Interestingly, no contact with healers or medical oncologists who practice alternative treatment methods was achieved, despite my persistent efforts on sending emails and making telephone calls. Within the context of economic crisis in Greece, people who experience cancer, either as cancer patients and/or medical consumers, find themselves at the intersection of biomedicine and alternative medicine, where they are able to choose which treatment option fits them. The ethnographic analysis is focused on the way that cancer patients and medical oncologists perceive and contextualize this choice. In the first part of the article, I provide an ethnographic starting point for my analysis. In the second part, I analyse the dominance of biomedicine and the construction of the biomedical subject. The third part, focuses on the ways with which alternative medicine is being constructed as the dangerous 'other' or as 'the right of choice'.

'I Chose this "Other Way"'

'It is another Wednesday morning in the field', I thought while entering the hospital's main entrance, only to be disproved as soon as I arrived in the third's floor cancer ward. I felt the agitation when I faced the doctors and the interns going in and out the ward's director office. 'What is going on?' I timidly asked John,[3] a young intern. 'Come with me', he said, 'and find out by yourself'. So I did. John entered room n. 3 with Dr Bella, one of the resident medical oncologists. 'How are you, Jenny?', Dr Bella asked the woman who was lying in the bed in front of us. 'Shitty fine, thank you', she replied cynically, with a blank stare. 'Mrs Prigou, 46-years-old, diagnosed with breast cancer, unknown cancer staging, admitted last night due to paralysis. She is refusing any diagnostic test or treatment. We administer cortisone and we have planned radiotherapy in order to treat the paralysis', said John, looking at me in a rather strange or even conspiratorial way as if he was telling me, 'did you get it?'. Jenny was diagnosed with breast cancer two years ago. She told me, 'I was fine in July. A month later, the pain started. In September, they discovered eleven tumours in my right breast and a doctor gave me only two months to live'. After the diagnosis, she accepted with many reservations to have her breast surgically removed; but then she decided to follow an alternative treatment. She said:

> 'I met a medical oncologist who treats his patient in "the other way" [alternatively], not chemo, radio and all these poisons. He said that he can cure me if I followed his instructions; specific diet, cannabis oil and physical exercise. And he also provided me with some "vitamins", you know, the only medicine that can cure cancer but of course

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[3] Following common anthropological practise, I use pseudonyms for my interlocutors, while I adopt a descriptive reference for my fieldwork site.

> it is illegal here in Greece, because if it were legal all that "piddly" doctors would be unemployed now. So, I chose this "other way". And you know what? I'm so fucking tired of trying to explain to everybody in here that I have the right to choose. I don't have to explain myself or justify my choices. How can anyone judge me?'

Jenny was judged as being 'irrational' by doctors for choosing an alternative treatment. In the medical discourse, alternative treatment is seen as the 'wrong choice', while Jenny's doctor was judged as 'dangerous' and 'immoral'. For Gellner, 'in modernity most people take the canons of rationalism and science to be the only way of thinking, while relegating everything else to the informal sphere' (Gellner 1974 quoted in Lazar 2006: 38). Discussing her chose treatment, Jenny told me:

> 'It costed us a fortune, but it was totally worth it. For one and a half year I was just like you. Healthy and pretty. And then, I was not. My doctor told me that there is probably a metastasis caused by the surgery (mastectomy) because cancer is transferred through blood.'

> How did you meet that doctor?, I asked.

> 'Well, we did our research, of course. We also met some healers, but nobody could provide these "vitamins". We have been told that these are the most expensive you can find in the market, most probably because they are obviously illegal but totally effective. I would have been cured if I didn't have that surgery. That's why I don't trust them anymore'.

I left the room and returned to the ward's director office, Dr Alexandris, with whom I had a long conversation. Referring to Jenny's doctor, He said:

> 'He is an immoral person. He is not a doctor. He looks for consumers to sell his "magic" illegal "mantzounia" [μαντζούνια, herbal mixtures] only to see his bank account grow. He used to be my intern, and this is the worst. He is now performing alternative medicine, maybe for the money […] Unfortunately, this woman [Jenny] is not his only "victim". All these years […] I have seen many patients who are hospitalised here only to die just because he sells hope in a very expensive price […] He has been expelled from the Hellenic Society of Medical Oncology, which means he cannot practice oncology anymore. He is totally immoral as he sells these mantzounia as vitamins, not as medicines and this is how he covers the illegality. He also should be charged for tax evasion; this is also illegal. What do you think, that you buy these "vitamins" for 800 Euros and you get a receipt? […] But he is not the only one. There are many out there, killing people without guilt. Some of them are doctors, others are "healers" […] They are all "agirtes" [αγύρτες, charlatans]. Since we (the Medicine) haven't cured cancer yet they will be more and more […]'

Dr Alexandris was angry with the medical oncologist who treated Jenny's breast cancer with "vitamins", but also with Jenny and the patients who choose an alternative treatment. Dr Kazou, another medical oncologist of the ward stressed other aspects of alternative medicine:

> 'People using this kind of methods are usually uneducated people. They usually live in a village far from the city centre, that means they live in the past. And of course, most

> of the times they are women! Even when you see a man patient, I believe that his wife made him forsake the real medicine. I can't explain it otherwise. I don't see any reason for anyone to make such a bad choice.'

Alternative medicine acquires chronical, geographical and gendered aspects and, therefore, it is constructing not only as the 'otherness' within medical pluralism but also as a practice that belongs to the past and not to the modern scientific present and future. In Greece there are famous stories coming from the past about people who pretended to be healers or doctors, selling the 'cure' for cancer. One of the most known stories is that of the 'miracle water'. In 1976, a 36-years-old lawyer claimed the discovery of cancer's cure in the island of Kos. The 'miracle water' was being distributed in Athens by tankers, and people would wait in line for hours to buy 'the cure'. Complaints were filed about the side effects and the medical associations stressed the danger of its consumption. On 30 March 1976, the 'miracle water' was officially banned as 'dangerous for the public health', the lawyer was convicted for impersonation of authority and illegal distribution of medicinal products. Selling over-costed non-medical products is 'contrary to the rules of documented and evidence-based medical science in accordance with the law' (N. 3418/2005). Still, there are many cases of doctors convicted for the violation of the medical ethics because they convinced cancer patients to follow methods of holistic treatment.

The choice between conventional medicine and alternative medicine is interpreted by medical oncologists as a moral choice in terms of 'right and wrong'. Doctors who follow alternative treatments are morally judged and expelled from official medical structures, as the legitimacy of their action is disputable. According to Italo Pardo (2000: 6), legitimacy as a social process that is culturally constructed, makes sense through an emic approach. In this case, the choice of an alternative treatment is apparently legal but morally illegitimate, as it acquires ambiguous contextualisation for both sides.

Biomedicine: Dominance, Medicalisation and the Construction of the Biomedical Subject

The 'biomedical model' is an expression that describes the dominant medical approach to health and illness in most Western healthcare systems. Since the end of the 18th century, healthcare has been formed by a perception of normality which is constructed through the supervision of the 'medical gaze' (Foucault 2003). According to Foucault, 'up to the end of the 18th century medicine related much more to health than to normality […] (while) nineteenth century medicine, on the other hand, was regulated more in accordance with normality than with health' (2003: 35). Conceptions of health and disease are formed in a way that health is negatively defined as the absence of disease. Hence, since medicine claims the power of constructing or redefining the 'normal', medicine operates as the dominant institution for medical control through the process of medicalisation.

The hegemony of the medical gaze, which arose in the 19th century alongside the development of the anatomo-clinical method, indicates the need for state-level medical policies. The medical gaze and knowledge are located in the structure of symptoms and signs. The symptom is the form in which the disease is presented: of all that is visible, it is closest to the essential; it is the first transcription of the inaccessible nature of the disease. For instance, a cough, fever, pain in the side and difficulty in breathing are not pleurisy itself but they form its 'essential symptoms', since they make it possible to designate a pathological state, a morbid essence (different, for example, from pneumonia) and an immediate cause (a discharge of serosity). The prognostic sign announces what will happen; the anamnestic sign, what has happened; the diagnostic sign, what is now taking place. Between it and the disease there is a distance that it cannot cross without accentuating it, for it often appears obliquely and unexpectedly (Foucault 2003: 90-91).

Since the 19th century, medicine has been established as science. Techniques such as the stethoscope and the microscope enable doctors to look 'inside'. Robert Koch identifies specific germs that cause disease in humans. The use of ether for anaesthesia and vaccination therapies to address epidemics were some of the greatest revolutions in medicine (Ross 2012: 14). Medicalisation rises in the first decades of the 20th century. At that time, scientific medicine was established, replacing the era of medical pluralism. As Klawiter writes regarding cancer, 'during the regime of medicalization, cancer treatment moved from the home to the hospital; surgeons were installed as the sovereign rulers of the kingdom; breast cancer was discursively constructed as a curable disease, and women exhibiting the "danger signals" of breast cancer were reconstituted as the new subjects of the regime' (Klawiter 2008: xxvii). In the 1890s, the radical mastectomy, a legacy of the progress of the 19th century surgery introduced by Halsted (Mukherjee 2011: 14), became the hegemonic treatment, as the removal of the lesion became synonymous to cure.

In this context, the biomedical approach does not recognise the patient as a whole, rather than as an individual with diseased parts. The patient is expected to comply through 'self-control, the understanding of "proper" information (devoid of "harmful" cultural and social ideas) and the adherence to (expert) biomedical guidance' (Confortini and Krong 2015: 1353); otherwise, as a 'matter out of place' (Douglas, [1966] 2002) s/he is constructed as a 'risky subject' and is morally judged for his or her choice.

The Dangerous 'Other' and the Right to Choose

Mary, a 72-years-old woman, lost her husband six years ago. He decided to follow an alternative treatment when he was diagnosed with lung cancer. She told me:

> 'We went to a healer who could provide us with some vitamins. He imported them from an unknown country, and they really helped my husband. His cancer was actually everywhere in his body, but the healer told us that these vitamins have the ability to detect a cancer cell that is created in the body, they strike it and destroy it without damaging healthy tissues […]'

Mary told me many stories about her friends who chose alternative treatment methods. She follows a holistic approach that includes, first of all, a positive way of thinking; then, physical exercise, relaxation and meditation, rawism and a daily use of enema in order to remove toxins from the intestine. She also shared her own experience on how she was diagnosed a pre-cancer stage but followed exclusively a holistic approach and 'never dealt with this again'. She believes that 'they [the oncologists] fight this [the alternative treatments] due to the lack of evidence'. But, she asks, 'What could be the greater proof than the fact that all herbs, with their beneficial substances, come from the nature?'

Dr Leontis, a medical oncologist who was one of my main interlocutors during fieldwork reverses Mary's argument when discussing the issue of evidence-based medicine. He says:

> ‘people seek the scorpion’s poison or whatever they assume to be “the cure”, according to current trend. This is what healers “use”: “the need for hope”. Chemotherapy has a bad reputation. This is a fact that we oncologist should accept. This reputation comes from chemotherapy’s toxicity but today we are able to deal with this. Another reason for this reputation is the result, chemotherapy didn’t use to work with such success as it does today. But do you know what’s wrong with all those alternative treatments? Every treatment must be based on evidence. Something that can justify why you do what you do. The argument “from my experience I know that this mantzouni (μαντζούνι) will cure your cancer” is not scientific. Science is the result of knowledge that comes from data. Data are collected through experiments […] In other words, we (the oncologists) have evidence, the others (the healers) don’t. And this is exactly the reason why this is totally immoral. Because they know that they don’t have any evidence that their “treatment” can cure cancer, and for me it is immoral to know that you sell fool’s gold and still do.’

It seems that evidence acts as a legalization process through which treatment acquires its moral and scientific status. Barry claims that ‘evidence’ has become an increasingly strong rhetoric in biomedicine in the last few years (Barry 2006: 2648). In *The Birth of the Clinic*, Foucault (2003) describes how the medical profession acquired prestige and power through ‘scientific’ knowledge, resulting in definitions of ‘normal’ and ‘deviant’ and the establishment of disease categories. Biopower operates through the production of knowledge but also through the production of a willingness to comply with the rules that knowledge has established. Self-discipline and self-surveillance regulate compliance with the norms but also to ‘confess’ any deviation from these norms (Pylypa 1998: 21-24).

Kalliopi was 32-years-old when she was diagnosed with breast cancer. She was terrified and confused about the ‘right choice’ to make. She visited three different medical oncologists only to realise that chemotherapy was the only treatment on offer. She said:

> ‘A friend told me about a healer in Italy who was treating cancer patients. “He is very famous but, most important, he saves lives” she said. I knew all the unpleasant side effects of chemotherapy, and that after chemotherapy I couldn’t have children, and that was the scariest. And not to die of course. I found a contact and I arranged to go to Italy to meet this healer. I didn’t care about the money, my husband had decided to sell the house he inherited from his mother, so money wouldn’t be a problem. But when I arrived in the airport my legs froze. Deep inside, I knew I shouldn’t trust a treatment which is non-medical. It was a treatment which was not approved from any official agency, it was based on some herbals. And everybody was criticizing me for this choice. All the oncologists I visited told me, “It is your choice, of course, you can try this charlatan but don’t come back to me when you will be close to death”. So, I decided to make the “right” choice. “Right” for whom I am not sure, though […]’

Choice seems to be at the stake in this debate between biomedical treatment and alternative medicine. For the patients, choice is a right. For the medical oncologists, choice entails negotiable moral aspects. According to the 2002 European Charter of Patients’ Rights ‘each individual has the right to freely choose from among different treatment procedures and providers on the basis of adequate information. The patient has the right to decide which diagnostic exams and therapies to undergo, and which primary care doctor, specialist or hospital to use'.

Dr Ivanos, a private practice medical oncologist, claims that:

> 'Patients have the right to choose which treatment is the best for them. The problem is that this alternative industry of health is growing rapidly and attracts unprotected (from the law) patients who will pay for any promise of cure without side effects. But when there is an exchange of money and the product is "too good to be true", what remains for us (the oncologists) to say is: the buyer should be careful.'

Choice of treatment, and by extension alternative medicine, indicates that rejection or acceptance of the biomedical model is a matter of personal ethics. Medical oncologists disapprove the choice of alternative treatments unproven by science, ineffective for curing cancer and totally harmful to the patients, including financially. However, patients who choose an alternative treatment consider this choice as a right. This conflict reveals the political aspect of knowledge which is produced within the context of biomedicine. Hierarchies of knowledge and the attendant moral rankings construct alternative treatment methods as morally illegitimate and dangerous. This complex relationship marks conflicting discourses embedded in a framework where legality and morality are connected, resulting in cultural shifts in the expectation of healthcare.

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Legitimizing Spiritual Healing: *The Right to Folk Medicine in Contemporary South Korea and Israel*

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In Korea and Israel, many people in hypermodern urban areas believe that illness can occur due to supernatural interventions, be it grudging spirits in Korea, or godly punishment for lack of observance in the Jewish tradition. Improvement of health is believed to be possible through venerating supernatural entities who can enhance personal prosperity. In the perspective of *musok* (Korean shamanism), patients of *shinbyŏng* (spirit possession sickness) can be healed only when they are initiated as *manshin* (shamans) and learn to communicate with the supernatural in self-controlled possession rituals. There are 300,000 practitioners of musok listed in their professional organizations, which means millions of clients who view such healing treatments as beneficial. Nevertheless, no such healing is proposed by scientifically trained medical specialists. Similarly, in the case of Jewish spiritual healing practiced through venerating spirits of *tsaddikim* (righteous men), there is no institutional medical legitimization to these widespread healing treatments. Should the perception of sickness and health be extended to include spiritual folk healers within the individual's right for health? Such a suggestion would probably be viewed as a mere provocation by most doctors, but through the anthropological lens, where we value the emic views of our interlocutors and avoid judging phenomenological understandings that unfold within our research field, we should at least consider it without bias.

The three common kinds of healing: by industrially produced chemicals, by medical intervention performed in modern hospitals, by traditional religious healers do not rest on the same cultural base and are not perceived parallel in the hierarchy of accepted healing methods. It is not merely because all modern medical interventions succeed and all traditional healing practices fail; rather, it is related to politics of knowledge production and control of means to maintain what Agamben (1998) calls the 'bare life' of people. Politics of meaning are central in this discourse no less than the need to maintain the bio-survival of societies. As explained by Agamben, in most contemporary hypermodern societies, governing élites decide what to include or exclude from public systems that focus on what Foucault (1979) discusses as essential control of citizens' bodies. This structure became the core of global anxieties during the recent Covid19 pandemic, when governments were criticized extensively for the ways in which they managed citizens' right to health services. During that crisis, traditional spiritual medicine was excluded altogether from the official medical discourse.

Most spiritual healers did not expect to be included in the biomedical frenzy that the pandemic had created. They accepted that being religious, spiritual healing is a private matter, outside the 'legitimate' health system. Folk healing, while legal, is not accepted as legitimate practice in modern medicine; vice-versa, what is legitimate, for example expensive medications, is not necessarily legal, when prescribed for the doctor's benefiting from the pharmaceutical industry (Pardo 2004). The delegitimization of spiritual healing is a political choice because there is little scientific research that demonstrates folk healing to be ineffective. Most healers are likewise disinterested in checking their methods through scientific measurements, and so their liminality prevails. They continue practicing in the community as *complementary* or *alternative* medicine, terms that inherently state marginality. Paradoxically, as in other cases of rituals and the sacred 'that which is excluded from the community is, in reality, that on which the entire life of the community is founded, and it is assumed by society as the immemorial, yet memorable, past' (McLoughlin 2010: 7). Thus, many kinds of premodern vernacular health care practices have persisted, including religious and spiritual practices.

Practicing religious healing is an attempt to regain control of the otherwise chaotic biologic situation, especially when modern medicine cannot help because the diagnosis is a chronic or terminal illness. The flexibility of vernacular religious healing makes it accessible and enticing even for urbanites who rarely engage in religious practice routinely. When medical doctors assert that they have no cure, even atheistic sceptic people might search for less scientific healing methods. This is when the help of manshin in Korea and tsaddik venerating Rabbis in Israel are most often requested.

I have followed groups of tsaddik venerators in Israel since the late 1990s, and Korean manshin since the mid-2000s. In spite of the Israeli case being a vernacular part of monotheism, while the Korean case reflects polytheism, there are similarities in the ways in which spiritual healing is perceived and practiced. Moreover, the response of institutionalized medicine in both countries is far from supportive, although in both cases folk healers do not demand patients to avoid biomedical treatments. Medical institutions in both countries eye the popularity of spiritual healing with suspicion. A famous Israeli doctor declared, 'folk healers are charlatans, who take advantage of people in their worst of times'. Marginalizing spiritual healers regardless their efforts to be incorporated as complementary to biomedicine has been documented in many other locations, for example, Tuva in Siberia (Van Deusen 2004). There, spiritual healers were condemned for 'superstition', while the main concern had been their unsupervised operation outside state apparatus. Governmental response was harsher in non-democratic societies, such as the USSR and South Korea's 1960-80s dictatorship, because then broad public legitimacy was not viewed as a factor to be considered.

Practicing Healing through Lived Religion

First, let us clarify that not all Koreans or Israelis employ spiritual healers. Most Korean Christians refrain from consulting manshin (some do it in secret), and many ultra-orthodox Israelis refrain from venerating tsaddikim. The legitimacy of these lived religions is a social construct, which like other kinds of legitimized practices are contextually possible, even when criticized extensively (Pardo and Prato 2019).

Healing through Blessings from Tsaddikim in Israel

In the Jewish tradition, health and illness are in God's control. While Judaism is monotheistic, there exists a category of supernatural entities who can mediate between people and God. They are spirits of righteous persons (*tsaddikim*), thought as being 'seated close to the seat of honour' of God, because of their outstanding merit while alive. Tsaddikim graves become pilgrimage sites, featured on amulets and sacred paraphernalia. Many pilgrims told me that by praying near the tsaddik's grave they inform his soul of the specific help needed; for example, easing a particular illness, or conceiving. There are specialized Rabbis who venerate tsaddikim in rituals that are usually performed on auspicious dates, such as the tsaddik's death anniversary (*hillula*). The most famous hillulas in Israel are those of Rabbi Shimon Bar-Yochai (2nd century AD), and the Baba Sali (1889-1984 AD). In April 2021, the hillula of Shimon Bar-Yochai, on a forested mountain, was visited by hundred thousand pilgrims. In one of the yards, a large ultra-orthodox group crowded on improvised tribunes to watch their Rabbi sing. Unfortunately, some of the structures collapsed and 45 pilgrims died. In the aftermath of the disaster, most interviewed pilgrims said that next year they will perform the rite again, as if to allow the souls of the victims to continue their pursuit of hillula participation.

On 17 June 2021, I participated in a smaller event, the hillula of Rabbi Shalom Ifargan, in the town Netivot. In sharp contrast with the mass hillula events that I had observed there twenty years earlier, this time there were around a hundred participants. Still, one could observe different levels of religiosity. As I have explained elsewhere (Sarfati 2018), Jews can define themselves on a continuum from ultra-orthodox, through observant, to atheist. In this hillula, there were at least three people seated on wheel chairs, who came in hopes for a healing miracle, and several others, who specifically asked blessings for hospitalized relatives. The online live-streaming of the event, which has become common practice since the Covid19 outbreak, hosted around 4,000 viewers, and the video was shared more than 1,000 times. Within the 4468 comments that were posted during the event, more than half included the words health (*bruit*), or healing (*ripui/refua*).

Before the event, the Rabbi had posted on his Facebook page a video invitation to send personal requests. Among these, many included the specifics of illness or injury. A touching request was sent by Michel Msika saying,

> 'Respected Rabbi, please bless my granddaughter Shira-Haya, daughter of Keren-Marcel. She was injured very badly on Mt. Hermon 15 months ago and is still not communicating. We hope that she will be up on her feet and communicating with us. Thank you respected Rabbi'.

A request by Nati and Gili Branes read,

> 'Please, I beg you, pray for my daughter Shira, who had, exactly a year ago today, a terrible car accident and is since then in comma. Please pray for salvation and heavens' pity. With the God's help, a miracle will happen and she will wake healthy in body and soul, Amen'.

Such requests suggest the strong belief of some venerators that the Rabbi can perform miracles.

Healing through Possession by Spirits and Gods in Korea

In the shamanic perspective of Korean vernacular religions, when supernatural entities are venerated properly, they bless the venerators with good health. If they feel neglected or not respected, they might inflict illness. The cosmology of musok does not have a fixed hierarchy. There is no supreme god among the multiple entities venerated. Each person has a unique pantheon, in which ancestors are personal guardians. Natural elements such as a mountain, or star constellation are venerated by all manshin, but not always with the same intensity. Most manshin are female, while most spirits are male. Mythic creatures, such as the dragon king, are expected to behave as their persona in the myths. For example, if they are described as companionate healers, like princess Pari, an abandoned daughter who after many hardships comes back home and cures her dying father, then the manshin can ask them to heal their patients (Pettid 2000). The communication is based on possession-trance, where the supernatural entities descend into the body of the manshin and she conveys their message. This act is called *opening the gate of words* (Bruno 2002).

When there is need for healing, the manshin asks the spirits to check if a supernatural grudge or disharmony had caused the problem. This can be an angry spirit that dwells in the house, or an ancestor who had not received proper ancestor rites. In such cases, the spirits that surround the manshin can help negotiate how to appease the supernatural entity. If the manshin understands the cause of disharmony, she can prescribe the exact act needed to solve the problem. For example, a spirit of the place can say that it is hungry, and ask for offerings of rice and water. An ancestor can ask for a commemoration rite in her death anniversary. A mountain spirit can ask for offerings to be placed on a sacred rock. The symptoms of the disease might require intervention by biomedicine, but the cause for the affliction needs solving in a spiritual manner. If a person ignores the signals that supernatural entities send, for example through an illness, then the condition might get worse, even deadly.

The Performative Aspect of Spiritual Healing

The practices used to heal or enhance health by Rabbis and manshin have structural similarities, but not necessarily similar visual effects. Both Rabbis and manshin offer different scales of rituals, from short individual consultation to full-scale long rituals. While in the monotheistic tradition there is no visual rendering of God, and the tsadikkim are portrayed through realistic photographs and paintings, in Korea supernatural entities are painted in exaggerated cartoon-like style. Moreover, the encounters with healers are very different. The Rabbi advices patients to give alms and read biblical verses. He does not claim that he can channel the tsaddik's spirit directly through his body at will during the meeting, nor does he deliver the spirits' words, but these sometimes appear in dreams or through interpretation of certain religious texts (Bilu 1997). In contrast, during kut rituals, the manshin assert that the spirits have descended into their bodies (*shin-naerim*) and are available for questioning and petitioning directly.

In both musok and tsaddik veneration there are pilgrimages to sacred places. Tsaddik veneration is mostly performed near remote gravesites in Israel, Morocco or Europe. In Korea, prayer sites are mostly mountains and beaches for spirits of nature. The immense importance of the tsaddik pilgrimage could be witnessed in September 2020 during the hillula of Rabbi Nachman of Bratslav, who died in 1810 and was buried in Uman, Ukraine. Due to Covid19 precautions, the Ukrainian authorities had closed the borders, but thousands of Jewish pilgrims flew to neighbouring countries in hopes that overland borders would be less supervised. The Ukrainian authorities placed policemen to prevent the pilgrims' infiltration, and so the pilgrims stayed camped a few weeks until deported. In a media interview, Israel Shnor, a pilgrim who was held in Belarus, explained his view on performing pilgrimage in times of global health anxiety saying,

> 'all the people that you see here, and there are many more that you do not see, never thought not to arrive. With all due respect, we have a tradition of more than two hundred years' (*Ynet* 2020).

In Korea, the dedication of manshin to pilgrimage can be seen on every sacred mountain, through the summer rains and winter ice. Even elderly practitioners climb the steep slopes to pray under a large rock, light incense by a waterfall, or stand praying lengthily in cold ocean winds.

The performative means by which Rabbis and manshin mediate the supernatural powers are similar. In both religious rituals, the healers pray, sing and light candles. They sway and move around the ritual area, talking to the audience, promising success and healing. In such events, there is always food. However, in the Korean case, the food items are viewed as offerings to the spirits, while in the Jewish case they serve as gifts among the human participants. In both Jewish hillula events and Korean kut rituals there are moments of heightened emotions when participants attest that they feel the supernatural interventions within their bodies. Similar feelings were expressed by interviewees in the two different belief systems, 'feeling the hairs on my arms stand on edge', 'feeling warmth inside my chest', 'everything around looks brighter'.

One major difference between the two creeds is that the Korean practice involves possession-trance induced through drumming and dancing; appeasing the supernatural entities is achieved through entertaining them with dangerous acts such as standing on knives, feeding them delicacies and sacrificing animals. In tsaddik rituals, there is no direct reference to possession or trance; rather, the Rabbi delivers his requests to the tsaddik and God without channelling their responses; the veneration gestures do not include sacrificial animals (although these are mentioned in ancient texts); the main acts of worship are prayers, tales from the Old Testament and religious songs. In both Jewish and Korean rituals there is extensive usage of ancient dialects. Not all audience members understand the texts, but ritual organizers and practitioners are expected to master them.

The Interaction between Folk Healing and Modern Medicine

Tsaddik venerating Rabbis and manshin do not promote spiritual healing as a substitute to biomedicine. They suggest that supernatural interventions expedite the healing process, point to the best medical-care providers and prevent future deterioration. Recently, many manshin and Rabbis have taken Covid19 vaccines, and this was documented in the media to convince the public that vaccines are legitimate and safe. Nevertheless, the common perception of most biomedical staff is that folk healers might prevent the proper treatment of patients. This view prevails regardless the fact that there is no medical research aimed to prove spiritual healing as harmful. The objections rest merely on paradigmatic assessments and hearsays. Spiritual healers accept the authority of modern medicine, while at the same time they openly criticize its shortcoming and relate to it as narrowminded. In a rationalization structure similar to other cases discussed by Pardo and Prato (2019), the healers view their occupation as a performance of personal morality.

The vernacular nature of these traditions allows the healers freedom from institutional supervision. The biopolitics that dictates delegitimization and marginalization of spiritual healing in the medical systems of hypermodern societies has not prevented millions from using it in the urban centres of South Korea and Israel. The contradiction between scientific and vernacular medicine does not exist in the worldview of these contemporary spiritual healers. They are legitimized at the grassroots level and enjoy the cultural and financial support of their many patients.

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Long Covid/Long View: Searching for Legitimate Care

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This article examines the experiences of Americans seeking health care during the Covid-19 pandemic, particularly those finding themselves still sick from the effects of the virus in cases of Long Covid, also called Long Haul Covid. The question becomes what happens post pandemic, particularly to those who are still suffering from physical effects of the Covid virus but also for health care in general and the concomitant questions of legitimacy?

History Repeats Itself

History records the lasting effects of pandemics, even on subsequent generations. The loss of family members in their prime affects a family, a community and a nation for generations. A look back at the 1918 flu epidemic shows that issues such as masking and social distancing fostered questions about legitimacy that were as controversial then as they are now. In a 2021 article in the *American Journal of Public Health*, the authors draw the following parallels to the 1918 epidemic and the Covid-19 pandemic: ‘In 1918, as in 2020, mortality was higher in the poor, in African Americans and Native Americans, in health care workers, and in workers in crowded occupations. These patterns, observed for most infectious diseases, reflect societal inequalities and inadequate occupational safety measures’ (Morens et al. 2021: 1092).

Descriptions of long-term symptoms in 1918 sound familiar to present-day sufferers: ‘We were leaden-footed for weeks, to the point where each step meant a determined effort […] It also was very difficult to remember any simple thing, even for five minutes.’ Other survivors spoke of ‘loss of muscular energy’ and ‘nervous complications’, as well as periods of apathy and depression, tremors, restlessness, or sleeplessness. By comparison, the same or similar symptoms are reported by Long Haul patients today. On 16 September 2020, a Long Covid patient tweeted the following: ‘Day 163 post Covid. I managed to walk for 20 minutes without chest pain while keeping my heart rate below 120’ (Spinney 2020).

The present study identifies six female respondents with definite or suspected Long-Haul Covid diagnoses. At the time of this study (Spring and Summer 2021), sufferers from this condition were hard to identify, making the perceptions of these women all the more important in understanding both the illness itself and its societal implications. Their experiences show the complexities of an already beleaguered health care system, taxed to the limit not only by the pandemic but by politics. It is as difficult to find legitimate care now as it was in 1918 for an illness that is new and complex. It is particularly difficult for the poverty class for whom the poverty of opportunity for health care is a glaring issue of legitimacy.

The Health vs Politics Clash for Legitimacy

Healthcare and Politics conjoined in the midst of the Covid pandemic. On 6 January 2021, the United States Capital was attacked in a riot by a crowd questioning the legitimacy of the 2020 Presidential election. It was no accident that this riot occurred after a long period of shutdowns and arguments concerning the Covid virus and the legitimacy of governmental response. Raising fundamental issues in the anthropology of legitimacy (Pardo and Prato 2019 and contributions in Pardo and Prato eds 2019), the country is so divided that the citizens cannot agree on the facts. Some even question whether or not the riot was a riot or if the pandemic is really a pandemic.

In the midst of the dual crises, Long Covid sufferers were seeking help for symptoms that no one understood and that many questioned. It was under these circumstances that the subjects of this study were seeking care that went beyond their original illness. It was in this uncertain environment with its accompanying plethora of information and misinformation that these women were often pushed to find their own answers concerning treatment.

The American Health Care System

Pandemics bring out the best of us and the worst of us — or both unity and distrust, as it has been observed during the discussion of the Covid-19 pandemic at the IUS Workshop on *Legitimacy: The Right to Health* (Tuscany, Italy, September 2021). In America, there are those who do not believe that healthcare for all is a right or a governmental responsibility. Moreover, there is a prejudice against people who live in poverty, and the American healthcare system is no friend to the working poor. Poverty in America does not simply refer to money. Poverty is a way of life that denies opportunity, including for medical care, to a class of people who live in the land of the American Dream where all of those who work hard enough are supposed to succeed but do not. The effects of Covid-19 on people of poverty have been out of proportion to the general population, not only in the first wave of the infection but also in the aftermath. In order to understand the lack of opportunity, it is important to examine the health care system itself, the treatment of the poverty class in previous pandemics, and the experiences of patients who are suffering from the residual symptoms of Long Covid and are looking for legitimate treatments.

The American Health Care System is fragmented at best. The system is a patchwork of public and private entities, and it is not universally accessible to its citizens. The majority of Americans who are insured are covered by private insurance plans through their employers. Government funded Medicare and Medicaid provide health care coverage to the elderly population over 65 and the disabled. The government also funds coverage through the military and through Indian Health Services (Tunstall 2015). Coverage for these groups has come from hard fought battles for legislation initiated by those groups, but in America there are always constant battles about who 'deserves' coverage with a particular suspicion that the unemployed do not deserve governmental health care because they are lazy and unemployed and do not want to work.

A February 2021 Gallup/West Health poll indicated that nearly one in five U.S. adults, which is 18% of the population or 46 million people, would not be able to pay for quality health care if the need arose. That same 18% reported skipping needed health care or cutting back on necessities such as food because of cost in the period that covered roughly the first year of the Covid pandemic. The current measure of healthcare unaffordability is higher among Black adults (29%) and Hispanics (21%) (*Gallup* 2021). It has long been recognized that healthcare is the financial 'back breaker' for the lower economic class in the United States. The poverty of opportunity for health care is a direct result of financial poverty. However, the cost of healthcare in America is so extreme that there are even many instances of middle-class families losing their homes or accruing insurmountable financial debt because of catastrophic health issues.

Healthcare has long been a political problem in the United States. The issue was addressed by the Clinton administration, but it was not until the Obama administration passed the Affordable Care Act (ACA) that the federal government was able to expand coverage. The ACA provided opportunities for insuring more people, but geography became an issue as some states refused the federal funding for Medicare for political reasons, leaving the citizens of those states still with high prohibitive costs for insurance. The Trump administration tried to kill the Affordable Health Care Act (Obama Care) but was unsuccessful. In June 2021, the United States Supreme Court made its third ruling in favour of keeping the Act intact, signalling the last judicial challenge. The two political parties are left with the task of working through Congress to change the system either by strengthening the act as is or by establishing universal health care. In the meantime, the citizens are so divided on the question of coverage that some of the working poor, for instance, will not support measures that would be beneficial to them because proposed solutions are presented by the 'wrong' party.

The Gallup Poll indicated that over 80% of Americans, regardless of political affiliation, favour setting caps on out-of-pocket costs for both prescription drugs and general health care services for Medicare recipients and for lowering the qualifying age for Medicare from 65 to 60. Medicare for All is still a political football, with 60% of Americans supporting it but with a breakdown of 93% of Democrats in favour with only 19% of Republicans in favour. There is currently a move by the Biden administration to strengthen the Affordable Care Act itself with similar statistics of support between the two political parties: 59% in favour but with a breakdown of 98% support among Democrats to 15% support among Republicans. The majority of independent voters supported both concepts.

The end result of the health care problems in America is that poor Americans who have a catastrophic event such as a heart attack will be treated immediately in the Emergency Room. However, wellness care and long-term care for both minor illnesses and long-term diseases like cancer or diabetes is virtually unavailable for those living in poverty. Elderly people on Social Security, people with disabilities, Native Americans and members of the Military are the only people in America who have access to free health care. Catastrophic illnesses can cause financial ruin for the middle class and certain death for those in poverty.

Covid 19 and Poverty

What effect did this fragmented system of health care have on Americans living in poverty during the Covid-19 crisis? The existing system was difficult to navigate at best during the pandemic but particularly for those living in poverty who were dealing with insurance issues, transportation issues, lack of health care before the pandemic, job loss and homelessness. There was difficulty in getting tested for a diagnosis. There was difficulty in getting treatment. There was difficulty in getting vaccinated. One study conducted at the University of California showed that during shutdowns, wealthy areas went from being the most mobile before the pandemic to the least mobile, while the poorest areas went from being the least mobile to the most mobile. The reason for this change was because the wealthy could go home to quarantine, but the poor had to continue to work to support themselves and their families. Therefore, the poor workers, who were often categorized as essential workers, basically enabled the wealthy and middle classes to stay home (Weill et al. 2020).

The authors of the California study also noted that there is an intersection of income and unequal access to information, including issues surrounding appropriate measures for avoiding exposure to the virus, such as social distancing. Many poverty class citizens live in conditions where social distancing is impossible. Many do not understand the value of social distancing. Many citizens in general question the legitimacy of the governmental mandates for masking and shutdowns and will listen to the gossip of neighbours rather than the medical community. Poverty of information is a by-product of poverty of opportunity. Citizens who live in pockets of poverty sometimes do not know how or where to get information and often do not trust ‘official’ information from the government when they are made aware of it. Vaccine reticence is the most recent effect of the poverty of opportunity caused by lack of information or misinformation in a poverty-stricken community. A further intersection where financial poverty affects information and opportunity, is in a prevailing suspicion that Covid is a governmental lie and that vaccines are dangerous experiments. Typically (Pardo and Prato 2019), lack of information or inconsistent information causes questions about legitimacy.

The difficulties brought on by Covid and subsequently Long Haul Covid underscored what was already a poverty of opportunity for the lower classes in America. The Center for Disease Control (CDC) describes the issue this way: ‘Every community must prepare for and respond to hazardous events, whether a natural disaster like a tornado or disease outbreak, or a human-made event such as a harmful chemical spill. A number of factors, including poverty, lack of access to transportation, and crowded housing may weaken a community’s ability to prevent human suffering and financial loss in a disaster. These factors are known as *social vulnerability*.’ (CDC 2021).

The Long-Hauler Search for Diagnosis

One present-day definition of Long Covid is ‘not recovering for several weeks or months following the start of symptoms that were suggestive of Covid, whether you were tested or not’ (Spinney 2020). Five of the six female respondents with definite or suspected Long-

Haul Covid diagnoses currently live in the urban area of Knoxville, Tennessee U.S.A. The sixth is a native Knoxvillian currently living in San Francisco, California.

All the interviewees were healthy and active before contracting Covid. Some were athletes. A predominant theme that emerged from all the interviews was loss of activity. The respondents missed their former active lives emphasizing that the primary, perhaps the only universal, symptom of Long Covid is a debilitating loss of energy. Another common theme was shock at getting over Covid only to have it return, usually with worse symptoms than initially; the recurring questions were, ‘Why am I still sick? When is this illness going to stop? Why me?’ Finally, the most important common theme came with the questions, ‘Why can’t the doctors tell me what is wrong with me?’, ‘I will do anything I need to do; just tell me what to do. I don’t care how hard I have to work—what do I need to do?’, ‘If this is a permanent condition, tell me, so I can learn to live with it.’ It was not until the Biden administration took office that organized research was sponsored by the government. Most of the work in the field seemed to be by doctors who were suffering from Long Haul Covid themselves. Grassroots groups flourished, particularly on-line, as sufferers banded together to try to learn from each other. It was easier to trust a fellow sufferer than to trust the medical community, which, particularly in the beginning, seemed to be floundering.

The interviewees’ responses show great difficulties in dealing with Covid from the beginning of their illness through their current situations with Long Covid. Another universal issue is that Long Covid patients tend to have recovered, seemingly completely, from the original illness, only to have it return with a wide variety of symptoms later. Often, the original illness was comparatively mild. None of the respondents in this study was hospitalized.

The Search for Legitimate Care

Medical practitioners have seemed to be surprised and, at least initially, unable to diagnose or treat Long Covid. Each of the respondents reported difficulty in getting a diagnosis. The earliest Covid-19 case in the group lived in San Francisco. There was difficulty in those early days (March 2020) in getting a Covid-19 diagnosis because it was a new virus and because the city and its medical facilities were shut down. The initial infection lasted approximately two weeks, and after a month, this respondent seemed to be well. However, by November, the Long Covid symptoms hit with a vengeance at a time when nothing was known about this condition. The doctors tried treating the symptoms but had no idea why the symptoms were occurring and were unable to give a reliable diagnosis. Vitamin B12 deficiency was quickly identified for the San Francisco participant and later for two of the other respondents. All three were given high doses of the vitamin. Subsequent tests showed an increase in the vitamin in their systems but negligible improvement of symptoms such as neurological issues and debilitating fatigue.

All of the respondents reported extreme fatigue. The San Francisco respondent had been a long-distance runner but became unable to walk a city block when the symptoms were at their worst. The two oldest respondents were competitive tennis players who found themselves unable to play as long or as often or as well as before. One respondent recounted shopping for groceries but immediately returning to her car because of extreme fatigue. All respondents reported that this fatigue has stayed with them, and they worry that it is permanent.

At least four of the respondents reported that they felt that they were not heard by their doctors. They felt that gender was an issue as two of the respondents reported that they were treated 'like little girls' while another said that she was treated like a hysterical woman. The San Francisco respondent broke down in tears, and the doctor's response was, 'What are you afraid of? That you are not going to be able to walk?' Actually, that was her fear.

The symptoms among the respondents varied. Only one reported that both she and her husband lost their senses of smell and taste. Two of the respondents reported 'heavy legs' and neurological symptoms in both their hands and legs. One respondent could only sleep in a recliner and found that she could not have anything touching her skin because of the pain. Three of the respondents reported 'brain fog' and an inability to complete the simplest of tasks. All the respondents complained about the debilitating fatigue that kept them from their usual activities.

Economics and the Search for Legitimate Treatment

Economic circumstances were woven into the ultimate treatments for these respondents. The wealthiest of the six is being treated by a homeopath, an osteopath, a physical therapist, a chiropractor, a psychologist and a general practitioner, with additional advice from doctors in the family. Much of this care, particularly homeopathy, would be economically out of reach for those living in poverty. The poorest of the six were trying to return to work while fighting the symptoms and doing their own research. The disparity in treatment was clear. The wealthiest respondent was put on disability by her doctors and received disability payments from the government. She was given these payments for over a year. The poorest of the group fought the symptoms trying to return to work. One was a pre-school teacher who was taking as many vitamins as she could find while trying to return to work, regardless of the fatigue and brain fog that she was suffering. One, who was suffering some of the worst symptoms, was trying to go to college while still maintaining a large household. She spent a great deal of time in a recliner, the only place she could stand to be, crying and feeling guilty because she could not take care of her family. Depression was an integral part of this and other participants' day to day life.

Conclusion

One hundred years later, there are still anecdotal family histories chronicling the loss of family members to the Spanish flu either from the flu itself, the long-term effects of the flu which included either permanent physical damage or even suicide. One hundred years later, there is still a world-wide poverty of opportunity for the poor in relation to basic health care much less care for residual effects like those suffered by those with Long Covid. Studies by Channa in India (2022) and Kayaalp Jurich in Turkey (2022) show the universal quest for legitimate care and the argument for the right to become healthy even for those living in poverty. However, studies in America seeking legitimacy in health care in the past and in the present show that America is not really the shining light on the hill, the beacon to show the rest of the world how to live, that it once purported itself to be.

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The Views of Selected Tennesseans on Universal Health Care as a Right.

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> And would it have been worth it, after all,
> After the cups, the marmalade, the tea,
> Among the porcelain, among some talk of you and me,
> Would it have been worthwhile,
> To have bitten off the matter with a smile
> To have squeezed the universe into a ball
> To roll it toward some overwhelming question […]
> (T. S. Eliot, from *The Love Song of J. Alfred Prufrock*, 1915)

This is a qualitative interview study regarding the opinion of five participants as to whether health care in the United States is a right. Health care is not a right in the US, either legally or in practice. This causes disparities which correspondingly affect the perception of most of the participants as to the overall legitimacy of the health care system.

This investigation is primarily a qualitative interview study (McCracken, 1988; Spradley, 1980). An important element involved the basic participant responses to the interview question. As Merleau-Ponty said, 'The perceived world is the always presupposed foundation of all rationality, all value and all existence' (1964: 13). C.W. Mills wrote in conclusion to his work *The Sociological Imagination* (1959), 'Be a good craftsman. Avoid a rigid set of procedures. Above all seek to develop and use the sociological imagination' (from Bogden and Taylor 1975: 40).

Chaos mathematics is the most recent development in buttressing the case for qualitative research. In his *Chaos: Making a New Science,* Gleick states:

> The first chaos theorists, the scientists who set the discipline in motion, shared certain sensibilities. They had an eye for pattern, especially pattern that appeared on different scales at the same time. They feel they are turning back a trend in science toward reductionism, the analysis of systems in terms of their constituent parts. They believe they are looking for the whole (1987: 5).

Five selected participants were interviewed in Knoxville Tennessee (USA) regarding their attitudes toward universal health care as a right. All were habitual patrons of a local McDonalds and met there regularly for breakfast. They were from a variety of backgrounds fostering a varied set of responses to the interview question. All were good communicators and were either retired or had been gainfully employed for a period of several years. Their insights provided both an understanding of their view of the health system in the United States and a glimpse into its ingrained lack of legitimacy in their eyes. This study elaborates on their primary answers with details from scholarly literature. Discussions with the participants took place inside the restaurant at remote tables as there were no more suitable places found due to covid restrictions.

All participants were given pseudonyms and all sessions were recorded. The individuals featured in the study were Rico, Douglas, Sleepy, Tippi and Candy. Rico is a wealthy retired businessman who did well enough financially to retire over twenty years ago while still in his fifties. He moved from his home in New York to retire in Knoxville. He is a skilled communicator both in the usual company at McDonalds and with strangers. He has reached the age that he receives Medicare, a federal program which covers approximately 80% of individual medical costs. Douglas, born in Miami, Florida, is a retired accountant and money manager who lived in Great Britain for several years in his youth. He is exceptionally succinct and demonstrative in his views. He has health coverage which he pays for privately. Sleepy was born in Poughkeepsie, New York, and moved to Tennessee some years ago. He is a homeless man who spent six years in the U.S. Army but who has drifted in and out of employment since then. He sleeps in a tent behind a nearby church. Sleepy has health coverage which he terms 'adequate' from the temp agency which employs him on an intermittent basis. Tippi is a retired professional who continued to work in a winery and in a telephone bank for Talbot's, a retail store. She received health care insurance through the so-called Obamacare (Affordable Care Act–ACA). Tippi recently underwent chemo and radiation treatment for cancer. Candy is a worker at McDonalds who takes responsibility for cleaning the large customer area in the establishment. She has been notable for the thoroughness of her cleaning, spending considerable extra time disinfecting booths because of the covid epidemic. Candy is a single parent. She has private insurance partially supplied through government agencies, but none through her employer.

Three of the interviewees felt that health care in the United States should be a right. One believed that citizens should have a choice as to whether to have private insurance or universal health care. One believed that health care was not a right and could not become one unless it was enacted as part of the U.S. Constitution. The themes that ran through the interviews were 'a legitimate right', 'not a right at all' and 'any legitimate solutions which would lead to universal health care'.

A Legitimate Right?

All but one of the participants believed adamantly that health care was a right. Their responses to the question as to whether universal health care should be a right were unequivocal. This concept that healthcare is a right has been envisioned for many years. The founding documents of the United States provide support for universal health care. Men possess, according to the Declaration of Independence, 'inalienable Rights, among these are Life, Liberty and the pursuit of Happiness'. The preamble to the U.S. Constitution states that part of its purpose is to 'promote the general welfare' (Cornell University n.d.). In 1944, Franklin D. Roosevelt proposed legislation that included the right to a standard of living adequate for health and wellbeing, The beginning of a worldwide movement for health care was first formally announced worldwide in 1949 by the United Nations in its Universal Declaration of Human Rights. It formally proclaimed that health care was a right, and that all nations were obligated to promote the physical well-being of their citizens to the fullest extent possible (United Nations World Health Organization 1949). After this Proclamation, the International Covenant on Economic, Social, and Cultural Rights, containing similar language favouring universal health care, was signed by the U.S. in 1977.

President Bill Clinton attempted to pass a bill during his term in office, but in spite of popular support, it was savaged by negative advertisements paid for by elements of the medical establishment. Midterm elections swept Republicans into office and the bill failed. Another push toward more citizens having access to health care was made by President Barak Obama in 2010 through the ACA. The act substantially increased the ability of uninsured, underinsured, and uninsurable persons to obtain insurance policies. Shaffer states that 'The ACA established universal coverage for health care as a national goal and delineates the disposability of individuals, employers, and the government to contribute to its cost' (2013: 970). It did not provide universal health care but did extend health benefits to many persons who heretofore lacked them. Progress remained incomplete and many millions of the non-elderly population remained without insurance. (Woolhandler and Himmelstein 2017).

The most recent movement toward universal health coverage came during the 2019 Presidential primary campaign. Senator Bernie Sanders gained considerable support for a 'Medicare for All' plank in his platform. Sanders wanted the federal government to take over private health care insurance and replace it with a comprehensive, single-payer program. Under this plan, every U.S. resident would receive access to free medical treatment in almost every category of health care. When Sanders did not receive his party's nomination, the momentum of this movement was considerably diminished (Freedman 2020).

The struggle continues, and proponents of universal health care cite numerous reasons that it should be implemented. McLaughin and Leatherman state that:

> 'In the USA, studies published in leading professional journals consistently report that people with acute and chronic medical conditions receive only about two-thirds of the health care needed, and at the same time, that 20-30% of interventions are either unnecessary or of questionable benefit' (2003: 136).

One major reason for implementation for this circumstance of some form of universal health care is that single-payer care could lower the cost of health in the United States. Health costs continue to rise, approaching one fifth of the economy. Health insurance companies spend well over 10% of premiums on administrative costs vs. only about half that amount spent by public health programs. Canada and the United Kingdom, two countries that provide universal health coverage, spend less than half of what the United States did per capita in 2017. South Korea, also with universal coverage, spent only approximately a quarter of the U.S. spent per capita, yet provided coverage for its entire population. Kreier argues, 'One reason for the higher cost in the U.S. is the fact that 'single-payer' systems, like the one in Canada, and those with multi-payer systems and all payer systems incorporate procedures for setting rates, including countries like Germany and Switzerland which spend much less per capita than the United States' (2019: 210).

One comment made by most participants in this study was that the United States was one of the wealthiest countries in the world and should be able to afford easily health coverage for its people. Many other countries with a much smaller per capita gross national product provide universal coverage. The medical system in the U.S. even has adverse effects for foreign students studying here (Vakkai et al. 2020: 765). Another problem is that health insurance is a complicated purchase. The purchaser must choose between many policies with different benefits and shortcomings (Persad 2020). Health insurance itself has risen in price in recent years as has its corresponding deductibles. In 2017, 43% of working Americans were living in families which struggles to pay medical bills (Mukherjee 2019). Even asylum seekers have experienced a significantly deficient standard of health care in the U.S. (Rubio 2021). For the uninsured, hospital emergency rooms are providers of last resort, and an extremely expensive remedy for the hospitals. Importantly, universal health care might also obviate the huge number of bankruptcies caused by individuals' inability to pay their medical bills. Estimates are that an astounding 500,000 such bankruptcies are filed each year. Single payer healthcare would eliminate this injurious circumstance.

'It Ain't Necessarily So' (that Health Care is a Right)

Douglas strongly opposed universal healthcare as a right. He felt that, as it was not a right granted in the Constitution, it was not a right at all. His view has considerable support. The Declaration of Independence does not specifically say that there is a right to healthcare. The preamble to the U.S. Constitution, we have seen, states that one of its purposes is 'to promote the general welfare', but does not mandate that it must be provided. The Bill of Rights lists a number of freedoms that the government cannot curtail but does not provide any goods and services that citizens may receive. An argument presented is that although people need health care, food and shelter, this does not necessarily obligate others to make such provisions available. Food, for example, is not considered a right; companies are permitted to sell it, and it can be withheld from those who cannot afford it. Opponents also bring up the matter of increased delays in seeing a medical doctor. They present the prospective argument that in Canada, a country with universal healthcare, the average wait time to see a specialist is almost twice as long as it is in the United States (Canadian Institute for Health Information 2016).

Another argument against universal health care is that it promotes socialism. This argument centres around the belief that socialism exists when large government programs control major areas of society and thus intrusively control the lives of its citizens. According to President Ronald Reagan, '[. . .] one of the traditional methods of imposing statism or socialism on a people has been by way of medicine, behind it will come other federal programs that will invade every area of freedom' (Field 2011). A single-payer system could lower doctors' salaries over the salaries of doctors in single-payer countries like Canada and England (Knowles 2018, Locke and Duqueroy 2018). Finally, one criticism of single-payer health care is that individuals should take personal responsibility for paying for their own health care rather than turning to the government for this service.

Legitimate Solutions

All the participants in this study noted a tension that there was trouble in their nation, even though they personally had health insurance. 'We are a rich nation', said Tippi, 'and we should have health insurance for everyone'. These thoughts were echoed by Rico and Sleepy.

It should be noted that the United States is not without some forms of government health care. The Social Security program pays about 80% of most medical expenses for those 65 years of age and older. Supplemental insurance can be purchased which covers the remainder and can be deducted from Social Security (retirement) checks. Another program, Medicare, gives support for medical expenses to limited classes of low-income persons. Some states have programs to cover portions of their low-income residents. None of these approaches the concept of universal health care coverage. Linking coverage to employment only raises the possibility of a two-tier system and negatively impacts the possibility of universal coverage (Gorin 1997: 343). There are several plans used in other countries that provide universal coverage. Some countries, like Germany, have plans that require the entire population to purchase insurance. Some countries, such as Switzerland, fund their health programs directly through the government, with funding gained through tax revenues. Australia has a dual public/private system in which higher quality care can be purchased through insurance. There are many iterations of these policies though the world, though none has taken root in the United States.

Conclusions

Sadly, the United States is the only nation among the 37 O.E.C.D. (Organization for Economic Co-operation and Development) nations that does not have universal health care, either in practice or by constitutional right. Gorin and Moniz ask, 'What, then, is the future of universal coverage?' (2004: 43). Oberlander (2003), suggested that without significant change in the political environment, incremental reforms offer the best and perhaps only way of changing our health system. The avenues reform would likely take are:

1. Strengthen the Affordable Care Act. This could ensure all citizens, though through it would be more expensive overall as it would be implemented through private insurance plans.
2. Broaden Medicare. Medicare already exists for those 65 years of age and older. The bureaucracy and government framework already exist. This would be close to a single-payer plan, particularly if the agency is allowed to bid on pharmaceuticals and all medical costs.
3. Establish a National Health Service. This would be similar to the process of broadening Medicare, though would have the advantage of designing an agency prepared to deal with the needs of individuals of all ages.
4. Construct a private system designed for universal coverage with the government reimbursing the medical community for its expenses.
5. Establish a two-tier system, offering basic medical care for all and improved health care for individuals willing to pay for this service.

It is quite possible that great reform with 100% coverage will not materialize for decades in the U.S. political system. As Michael Moore pointed in detail in his film *Sicko,* a staggering

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number of the members of the U.S. Congress are receiving contributions for their re-election from the pharmaceutical companies and from organizations representing the interests of medically oriented corporations. These contributions make it nearly impossible to obtain universal health care in the United States. For political reasons the United States has chosen not to do that (Public Broadcasting System 2021).

It is apparent that the United States has been too mired in corporate corruption to make the necessary national reforms. Piecemeal changes have been bitterly opposed by conservatives in Congress and their allies in lobbying organizations. When President George Bush II instituted Part D of Medicare to help lower drug costs, the drug companies lobbied to allow them to establish pharmaceutical prices. Prices naturally remained high.

When will it end? Perhaps when a national crisis arises a progressive political block will be able to make major improvements. A national crisis has proven in the past to foster basic changes—after all Japan and Germany only attained universal health care after the end of World War Two. This is a sad way to look for reform. The United States may have reached a disastrous level of corruption with massive debt and expenditures that it will eventually implode financially. At present 23% of all federal revenue goes to pay interest on the national debt and repayment is further constrained by military expenditures (seen as representing somewhere between 35% and 50% of all federal revenues). It would be a sad thing if the United States went the way of Spain in the 1550s when King Philip declared his country bankrupt. This Spanish bankruptcy was due to massive federal overspending both domestically and in excessive military endeavours. Spain did not recover for centuries. A crisis would probably supply the United States with sufficient bipartisan support to establish a universal care system, but at what cost? The battle for universal healthcare is being continued regardless. The current struggle carries with it the seeds of success in adopting a program which provides for the medical care of all U.S. citizens.

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Health and People with Disabilities. A Medical Anthropology View

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According to Shuttleworth and Kasnitz (2006), the past years have seen a burgeoning world political and academic interest in the study of impairment and disability. Although prior to the 1960s anthropologists addressed the issue of disability in cross-cultural terms, it was during the 1960s that the anthropological focus on people with cognitive, behavioural and physical differences emerged. Between the mid to late 1970s and early 1980s, a group of anthropologists and medical anthropologists including Joan Ablon (1981,1984), Gay Becker (1980), Louise Duval (1984), and Nancy Scheper-Hughes (1979), among others, began publishing their work on people with various kinds of impairment-disability experience. In the early 1980s, Duval founded the Disability Research Interest Group of the Society for Medical Anthropology, which sponsors scientific sessions on disability at the annual meetings of the American Anthropological Association (AAA). Disability is now seen through the wider lenses set by WHO, according to which health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. In this perspective, the rights of People With Disabilities (henceforth PWDs), their right to social reproduction among other things, should not be assigned as favours based on philanthropy, compassion or charity but in terms of their full citizenship.

Various aspects emerge as a result of this point of view. An important issue refers to the influence of the socio-economic environment and the class structure on the distribution of mortality and morbidity, and consequently on the reproductive value of the labour force. Another one concerns how to deal with health problems and the social production of medical care. In the capitalist system, the dominant problem is the contradiction between achieving health and pursuing profit. For the sake of profitability, the process of commodity production devalues the health of the low strata, aggravates the destruction of the environment and produces goods that are harmful to health. The model of therapeutic medicine, with its functional individualistic approach, serves the interests of the capitalist system, as it obscures the factors that cause disease and promotes individual responsibility, accusing the victim of lack of discipline, self-control and will, which are key personal characteristics in terms of productivity growth. On the other hand, to the extent that medical care improves the level of health, the state is involved in the financing and provision of health services with the aim of contributing to the 'natural' reproduction of the labour force and the exercise of social control. The contradiction between health and profit is reproduced in the health sector, where the process of capitalist accumulation results in more and more for-profit companies penetrating the field and expelling small-scale service providers. In this context, a 'medical-industrial complex' is formed; based on profit, it pursues the commercialization of medical care and the development of an entire health care industry. The consequences are rising costs, excessive use of health resources, emphasis on technology expansion, insurance companies promoting risk-taking policies and creating a two-speed health care system regarding access to and quality of services.

In addition, I am thinking about the much-debated relation between doctor and patient. Doctors have power, and they claim a monopoly on the patient's body. Although patients may resist the doctors' prescriptions, they are faced with a double bond; on the one hand, they are those who judge and decide when to go to the doctor and, on the other hand, they have to follow his instructions. Every doctor is exposed during his undergraduate and postgraduate education to a set of values and rules of conduct that gradually compose his/her role as doctor. According to Robinson (1999), the physician, as a member of a special professional team and working in separate organizational formations (private practice, health centre, hospital, and so on), has professional and administrative restrictions that control his/her suitability and feasibility of the medical practice. In other words, the actions of the doctor are defined and limited by law, professional ethics, time, inter-professional relations and the organization of the exercise of legitimate power (Pardo 2000). On the other hand, the patient's behaviour, when s/he has already recognized her/his symptoms and adopted the role of the patient, depends on the perceptions of the origin and treatment of the disease, her/his socio-economic status and subjective characteristics. The various social institutions also play an important role in shaping the individual's perceptions about the origin of the disease and her/his attitude (and behaviour) towards the disease (and indirectly to the doctor). In this, family and school are the main actors.

On a similar line, it is important to take into account the role of lay health beliefs. We know that there are three main types of medical knowledge: professional, common (ordinary people) and alternative (traditional or non-Western). The second one focuses on the fact that professional knowledge has recognized that people's beliefs about their health are crucial to the course of the disease. Are there different lay health beliefs among different generations or different social classes? The basic sociological concept that helps us in our research on lay health beliefs is that of social representations. What are the social representations of everyday people about how they define health? In the 1970s, research highlighted the role of the metaphors people used to define health. The most basic were:

- Health as a destroyer, containing loss, isolation, disability;
- Health as a liberator, frees from obligations;
- Health as a stock that you inherit and protects you from disease;
- Health as balance and harmony.

I think this is important to understand that the way in which people interpret health has also moral dimensions; saying that someone is healthy is a moral discourse, because we mean that he is responsible, that he is capable of doing things (to work). Health, here, means that one has a responsibility not to give up, which may also be related to and derived from religious traditions.

However, social inequality regarding access to health care systems is extremely important. Health is considered a social good, so everyone should enjoy it and everyone should have access to the means to get it. But do they? The concept of health inequality refers to the idea that certain social groups have higher rates of good health and life expectancy than other social groups. Over the years, a theory has been developed of health as a social good according to which we should not focus on the individuality of patients and their bodies and health research and health policy should be directed to the economic, political and cultural institutions that produce illnesses. Thus, classifications of the disease are proposed based on the economic, cultural and social determinants of ill health and disease.

Inevitable inequalities focus mainly on the biological and hereditary background of each individual that brings about differences in health status and quality of life. Inequalities that appear to be unavoidable are also found in personal choices and attitudes toward health. On the other hand, the health inequalities that can be faced are centred on the social, economic and cultural factors of social differentiation that can be mitigated through appropriate policy measures. Recent anthropological approaches reject the notion of personal attitudes and behaviours as a cause of inevitable inequalities, as the former are directly dependent on external factors (economic, social, educational) that act as pockets of inequality and negatively affect personal choices, behaviours and appropriate information on health. The study of health inequalities is of practical and ethical interest to both health professionals and social anthropologists. By studying and explaining the phenomenon, they are able to identify several factors of good or bad level of health and help ethical philosophers to explore the ethical dimension of existing inequalities in health.

While the moral dimension of health inequalities should not be taken uncritically (Pardo and Prato 2019), the distribution of a population’s health depends on the modern expansion and quality upgrade of health services, on social factors and on factors of individual/genetic inheritance and luck. Social inequalities in health are related to the life cycle of the individual as the former start from the accumulation of risk and vulnerability at birth and can be exacerbated or mitigated by the intervening life experiences. Related to these, are explanations of inequalities which can be summarized in three categories:

First, interpretations of choice due to health. From this viewpoint, the state of health decisively affects one’s social position. Healthy individuals are more likely to have upward mobility, while those with poor health have a downward mobility; for example, those who had a serious illness in childhood have been shown to be statistically very likely to end up in a lower social class.

Second, cultural and behavioural interpretations. According to this approach, health is a dependent variable, in the sense that class differences cause health effects and not the other way around. Lifestyles differ according to social class, young people from lower social classes eat more unhealthily, while, as we move up the social hierarchy, the percentage of those who eat healthily and lead a healthy lifestyle increases.

Third, material interpretations. According to this approach, factors such as poverty, housing conditions, infection and working conditions determine health. Hence, inequalities related to health are not absolute and dependent on one but relative factor (for instance, income); that is, they depend on the coexistence of differences in power and status. Material inequality produces social differences that lead to stress, lack of self-esteem and insecurity, which undermine the state of health. The decisive factor is social cohesion, the higher it is the better health indicators.

Finally, a very significant issue relates to stigma. In Goffman's sense (1963), the Greek word stigma refers to a symbolic feature of people who are unable to maintain a respectable social identity because of this condition. There are three types of stigma: on the body, on the 'character or mind' (mental illness) and on an entire social group. The first two are about illness and disability and the third concerns groups that are considered 'contagious' such as drug addicts and prostitutes. Stigma emerges when there is a discrepancy between the potentially social identity and social identity as such, in the sense that the reactions of others 'vitiate' the social identity of the individual (spoiled identity). The probability of stigma depends on:

- The visibility of the symptoms and whether they are recognized by others;
- Whether others are aware of and know things about the disease (for instance, epilepsy);
- Whether daily interaction is hindered (for instance, stuttering).

Against this socio-medical background, PWDs are not only handicapped by physical barriers. They are also handicapped by social obstacles, such as the attitudes or beliefs held by other people (disabled or not), as well as by laws limiting their rights. A number of factors contribute to disability within a life course approach (Heller and Harris 2012), including, a) the age of onset of disability, b) whether disability is a condition that can come and go and, c) the fact that disability can also occur suddenly or gradually. In general, there are two approaches for theorizing disability culture, both with their respective key problems. Firstly, there are those who consider disability culture to be about challenging the cultural representations of disability that exist within a mainstream culture in order to achieve for disabled people the equal respect and value that is given to other members of society. Such a position clearly perceives that such cultural practices are not only about tackling stigma, but also about increasing equality of opportunity and outcomes for disabled people. The second approach to disability culture is about 'celebrating' disability as 'difference' (Shakespeare 2002). This notion of celebrating difference is very much connected with the idea of the positive 'disability identity', and as such is fully contested.

According to the Observatory for Disability Issues (2020), in practice people with disabilities face a number of obstacles as regards the health system and its services. In Greece, regarding the accessibility of hospitals, the obstacles that people with disabilities face concern the rooms of the hospitals but also the toilets for the patients, which are not adapted in such a way as to be accessible to persons with disabilities. In addition, there is no marking in Braille for the blind or partially sighted, and there is also no design for how people with disabilities will evacuate the building in the event of an emergency. Although there are ramps, their use is mainly for stretchers and for the transfer of patients by the nursing staff. When it comes to elevators, there is rarely provision for sound floor announcement as well as buttons in Braille. In addition to barriers related to the built environment, there are barriers also in terms of communication of patients with disabilities with doctors, nursing and administrative staff of hospitals. In particular, the deaf or hard of hearing face limitations in their communication with doctors and nurses since there is no provision for communication between them in sign language. Equally, there are no documents available in Braille; for example, one's medical history is an important document containing sensitive personal information and it is available in print or in digital format but not in Braille. The same goes for patient consent forms regarding specific medical procedures. While it is generally good that access is available to persons without social security with or without disability, the negative facts remain that:

- There is a large percentage of people with severe disabilities whose needs for medical examination or treatment are not satisfied;
- There is a heavy financial burden on households with private expenses for health benefits;
- There are shortages of health personnel, supplies and consumables on health structures due to cuts in public health expenditure;
- There are obstacles faced by people with disabilities and/or chronic illnesses due to the inaccessibility of hospital buildings;
- There are barriers that people with disabilities face as far as their communication with hospital staff is concerned.

Based on these, it follows that people with disabilities experience barriers to accessing their right to social reproduction and of course to their well-being as the main aspect of their health status. This is a condition that they have not chosen and try to overcome, while being unprotected and can count on the sole support of their personal will and their family context. One needs to wonder who is really disabled, these people or the society that excludes them?

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Covid-19 Pandemic, Health Policy and the Question of Legitimacy in Turkey

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For Weber, the concept of an ideal type is a fictive construction which is useful for comparative studies. The idea is to understand how the world and the people within it actually function. Portes explains that by ‘rubbing the ideal type against reality’, one can ‘establish whether theoretical expectations — implicit in the concept — actually hold’ (2010: 3-4). In other words, through ideal types, the researcher can investigate whether the assumptions are realized or not in real life. However, anthropologists are not satisfied only with the analysis of the actual life on the ground but they want to go further and see the ‘imaginary’ of the state or other institutions in their attempts to govern the social. This idea is eloquently explained by Prato who stated that ‘in order to grasp how a system actually works it is not enough to investigate the functional, or utilitarian, aspects of action; we need to understand what ideal of society and political system individuals aim to accomplish when they, for instance, bring to life a new political organization or advocate new forms of political action’ (2019: 32).

While the former approach — to see how the public react to the policies and practices — might be explained as one of the basic and conventional concerns of anthropology, the latter points out an emergent anthropology of experts in which the practices, institutions and knowledges of experts have become the anthropological concern (Boyer 2008: 39). Recently, we have been witnessing a widening discrepancy between the decisions of experts and actions of the public deviating from these decisions. Today, the confusion between what is legal and what is legitimate may be more than ever. New policies and practices are being enacted under the pretext of ‘state of emergency’ without having the consent of the public but under the disguise of experts (Prato 2020:8). This brings us to the question of the difference between legality and legitimacy which address different issues: what people see as legitimate in their everyday lives may not be legal, while, at the same time, what remains outside the borders of law can be considered as legitimate (Pardo 2000; Pardo and Prato 2019: 7).

This short piece is a reflection of my ethnographic study on health policies during the Covid-19 pandemic in Turkey, which was presented at the Workshop on *Legitimacy: The Right to Health* organized by Italo Pardo and Giuliana B. Prato in the summer of 2021. Here, my goal is to provide a brief explanation of my fieldwork in conversation with other contributions. The workshop aimed to analyse ethnographically the ways in which the right to health is addressed by authorities and is experienced by the people on the ground. My research has also tackled with the questions of what legitimacy or illegitimacy is attached to health policy in the public, and to what extent health policies that are imposed in the name of the common good are received as il/legitimate at the grassroots. The emergency situation that appeared with the outbreak of Covid-19 has made the health policies messier than usual, and the case in Turkey illustrates how new Covid-19 medicine policies introduced in the country have widely been accepted by the public but without having met the legitimacy criteria.

From the beginning of the pandemic, Hydroxychloroquine (hereafter HCQ) has emerged as the most controversial medicine for the Covid-19 treatment in the world: despite the lack of evidence for its efficacy and the scientific evidence of side effects, several countries have insisted on using it. After WHO stopped recommending HCQ for the treatment of Covid-19 in July 2020, the enthusiasm for the drug rapidly declined and the countries that used to be offering the drug to their patients eventually stopped using it. Interestingly, Turkey remained one of the countries that insisted on using the drug — time-wise longer and quantity-wise more than any country in the world. On 15 April 2020, Turkey's minister of health underlined that this standard treatment approach was unique to Turkey.

> No other country used the drug Hydroxychloroquine in the initial treatment of all suspected and positive cases (of Covid-19). We stocked one million boxes of the drug before we even had our first case. Also, no other country uses the drug Favipiravir, which is imported from China, in the way we use it (Koca 2020).[1]

The Ministry of Health established tracer teams with the goal of screening the chain of contact in the infectious disease, reaching people infected by the coronavirus, monitoring them and isolating the diagnosed for treatment. However, as the Covid-19 cases drastically increased in the country, the teams' purpose has turned out to be dropping a bag of drugs at the door of the Covid-19 patients.[2] What is so striking is that not only the Covid-19 patients who had positive PCR tests but also their contacts were given drugs. In other words, infected patients as well as people who had contact with patients were prescribed these drugs even if they had a negative test result.

Turkey's persistent use of HCQ has constantly been questioned by national health organizations to no avail. Until the first week of May 2021, the government continued to use HCQ for all Covid-19 patients and their contacts, which, according to my calculations, accounts for more than 5 million people. There have been so many issues to investigate ethnographically the legitimacy of the Covid-19 drug practices in Turkey: how is HCQ treatment received at the grassroots? What tensions exist, if any, between the government health policies and the public response regarding the HCQ treatment? How do the patients as well as the doctors react to the use of HCQ in the treatment of Covid-19? Do the patients consider the use of HCQ legitimate or not? These were the questions I sought to answer.

What is specifically relevant for the purpose of this *Supplement* is the question of how a medicine, which is internationally neither legal nor scientifically legitimate for the Covid-19

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[1] Koca, F. [@drfahrettinkoca]. 2020. Türkiye tedavide farklı bir yaklaşıma sahip [Turkey has a different approach to treatment] *Twitter*, 26 April, https://twitter.com/drfahrettinkoca/status/1250318172957208576 Accessed 1 July 2021.

[2] They were short of time and missing the sufficient number of personnel. The original team, which was supposed to comprise epidemiology investigators and tracers, was later on replaced by *muhtars* (heads of local governments), teachers and other public employees (see https://www.evrensel.net/haber/431209/etkili-filyasyon-yok-filyasyon-sadece-aile-icine-indirgenmis-durumda).

treatment, has gained any sort of legitimacy in a country. When scientific studies have raised serious safety issues of the drug, many countries in the EU banned the use of HCQ for Covid-19 outside of clinical trials.[3] And, scientifically speaking, there is no substantial evidence that HCQ has been effective for the treatment of Covid-19. Atalay (2019) argues that the decisions of international institutions such as EU and IMF might operate beyond the borders of nation states and effect local citizens and create problems of legitimacy. But what if we are witnessing an opposite situation here: the health policies of a country are in direct opposition to the international public health authorities, and the entire country becomes a clinical trial place by the hand of its own legitimate.

As discussed, and ethnographically demonstrated by many contributions to this *Supplement* (Arnold 2022, Mollica 2022, Prato 2022), the pandemic did not hit everybody indiscriminately. There are many differences and areas of inequalities in accessing health care in several countries, which have led to other inequalities. However, the drug policy in Turkey adopted by the government has been pretty egalitarian since the Ministry of Health has provided the same drugs to every citizen. At this point it is useful to make a distinction between the right to health care and the right to health, which was one of the basic questions discussed in the Workshop. With its generous supply of drugs, the Turkish government provided health care for everybody but this did not necessarily mean that the medicated patients were truly treated, bringing out the point that the right to health care does not automatically lead to the right to health. The government was trying to leave a positive impression on the public that the country had the sufficient infrastructure as well as vital skills to manage and control the pandemic. Its presentation of the drug as effective and necessary for the treatment of Covid-19 was an attempt to legitimise the drug and promote the view that the government has been well-prepared for a disease that has, in fact, no treatment.[4]

In Turkey, an alternative mode of healthcare based upon the western medical system is developed and introduced by the government — not by individuals and communities — and put into operation for the entire population. In this *Supplement*, we see the opposite examples coming from below, such as cancer patients in Greece (Varelaki 2022), food and health sovereignty movements in Mexico (Olson 2023); folk medicine in South Korea and Israel (Sarfati 2022). The alternative treatments in these communities are neither perceived as legitimate medical treatments nor supported by the government, but they are still widely practiced by millions of people who trust them. In Turkey quite the opposite has taken place. The officially legitimate medical policy of the government was not trusted by the public;

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[3] See https://www.ema.europa.eu/en/news/covid-19-chloroquine-hydroxychloroquine-only-be-used-clinical-trials-emergency-use-programmes

[4] Armstrong and Rosbrook-Thompson's (2022) ethnographic analysis of the public health programmes in the area of violence in London vigorously illustrates how people were sceptical of these programmes but they were united on the belief that the model could *demonstrate* success. They argue that the public health approach had the ability to *demonstrate* success, despite underlying questions as to its adequacy and legitimacy. Similarly, the Turkish government has combined the goal of *demonstrating* success with the goal of filling the vacuum in the treatment of Covid-19.

patients were sceptical about the drugs and hesitant about taking them, yet my fieldwork illustrated that, paradoxically, many took the pills despite their lack of trust, though they first consulted their doctors, friends, relatives or neighbours, or did research on the internet.

Rather than the drug's actual effectiveness (which nobody mentioned during my fieldwork), for some patients what mattered was the drug's ability to give a sense of control over the uncertainty of the pandemic and to offer a sense of peace of mind in their fight against Covid-19. As Channa suggested, in a situation of uncertainty, the legitimization of something is also associated with the desire of the sufferers for some kind of solace or support.[5] Several patients decided to take the drug after self-monitoring their health conditions. For example, a middle-aged female informant explained that when she and her daughters became sick, at first, they did not take the pills that had been delivered to them. They kept self-monitoring. When one of the daughters, who had asthma, got worse, she started taking HCQ, while the other daughter stopped taking the pills half-way through the course, when she felt better. They were the main actors in monitoring and managing their health risk, both prior to taking the pills and while taking them.

In brief, none of the patients whom I have met have uncritically or unconditionally accepted the drugs handed to them by the government.[6] The consent given to HCQ was always very partial and conditional (Rosbrook-Thompson 2019: 42). It was partial because the patients were doubtful about the efficacy of the drug as promoted by the government; it was conditional because the patients were ready to quit the drug as soon as they felt better. Therefore, the government's scientific legitimation of the pills was not automatically trusted and approved by the public.[7] The 'legitimacy' of the HCQ has not necessarily emerged from trust in the government; rather, it has depended on the daily life assessments, judgements and beliefs of patients in their struggle with Covid-19. This situation has created a discrepancy between practical acceptance and legitimacy; people might accept something even if they do not see it as legitimate and, as in this case, they do not trust the efficiency of the treatment.

Legitimacy is a very complex issue. As Pardo and Prato argue (2019), its borders are changing overtime along with the changes and expectations of the society. My ethnographic research in terms of how Covid-19 patients react to the government's policy of HCQ in Turkey also brings out another aspect of the complexity of legitimacy. Even though the political decisions are imposed from the top, this does not necessarily mean that they would be entirely accepted at the grassroots. As discussed by Pardo (2022) in this volume some official, legal source of information about what is legitimate says one thing; at the grassroots, the view of what is legitimate says another thing, based on people's lived experience.

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[5] I would like to thank Subhadra Mitra Channa for this comment about my paper when it was discussed during the Workshop.

[6] This is similar to what Spyridakis (2019) found in his fieldwork in Athens; he showed how the poverty programmes were seriously questioned from below in terms of policy and how citizens acted based on their own understandings.

[7] Krase and Krase (2019) and Kürti (2019) address the point raised by Pardo (2000) that democratic states need authority and must rely on citizens' trust in order to rule; however, in the Turkish case, we see that the citizens comply with the health policies of the government without trusting them.

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Negotiating Power over Human Bodies: Populism, People and the Politics of Health in Delhi

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Introduction

In this article, I foreground the political scenario in contemporary India following upon the nuanced and intricate discursive intellectual space created by Pardo and Prato though a series of closely sequenced publications (Pardo 2012; Pardo and Prato 2019, 2021) to interrogate the concepts of legitimacy enjoyed by power holders in the modern democracies. Chatterjee (2011: 8) has cited the philosopher Ian Hacking, who distinguishes between two meanings of 'norm'. The first in the general sense of what is right and good; the other in the statistical sense of what is the most commonly occurring and accepted state of affairs in a particular region or culture. Many power regimes take recourse to the latter in order to please the majority. The power of the 'norm-exception' is widely operative to accommodate 'co-cultural' conditions between the ruler and the ruled and also to 'establish a working relationship between formal law and people's cultural requirements' (Pardo and Prato 2019: 2). The formation of the Hindu right-wing regime in India, is directly rooted in this principle, critiquing the secular and formal constitution of the country and its legal system, as being influenced by western and not indigenous values. However, in the effort to create an unanimously accepted legitimacy for its rule the regime is facing problems because it is almost impossible to obtain a consensus on values and norms in a diverse and multicultural society like India — more so as Hinduism is not a doctrinal religion and has at best a fragile bedrock of consensus on what is meant to be a Hindu (Channa 2017). Even the propagator of the concept of Hindutva, Savarkar, did not link it to religion but to a geo-political identity (Walsh 2011: 201; Jaffrelot 1996: 28). Brass (1994: 23) points to Gandhi's use of 'transcendent Hindu symbols' to overcome the internal dissensions among Hindus. The Hindutva identity is, therefore, more effectively built as an oppositional identity to the demonised 'other'; primarily the Muslim, but now extending to other non-Hindus. But, again, the number of Indians subscribing to it is far from being a majority.

Under stress from an extraordinary calamity like the Covid-19 pandemic, the dissenters find legitimate avenues for expression as exemplified by the political turmoil during the pandemic. The failure of the state to protect those for whom it is responsible leads to increasing questioning of its authority. The material on which this paper is based is largely auto-ethnographical, based on my experiences as a citizen of Delhi and as one who experienced the Covid-19 pandemic at first hand in the city.

Legitimacy of the Ruler

The present right-wing regime of the Bhartiya Janata Party (hereby referred to as the BJP) came to power professing to model itself on ancient Hindu traditions and glory, as a religious nationalism (Thapar 2002: 21). The Hindutva movement shows ideological affinity to populism in that it showed 'hostility to the status quo, mistrust of traditional politicians, appeal to the people and not to classes and anti-intellectualism' (Laclau 1977: 147). It would, however, be wrong to presume that its legitimacy draws on religious identity alone. It actually derives from a combination of various factors that include disillusionment with the dynastical rule of the family of Indira Gandhi, widespread corruption in the public sphere and the lack of fit of the modern secular model followed by the Indian constitution with the majority of Indians, who are still steeped in feudal and parochial values. But no political regime in India can claim itself to represent the majority on religious/cultural grounds. The only goals and values that can actually cut across Indian society are those based on instrumental and immediate needs, including food, water, clean environment and health.

Being well aware of these conditions, the central government floated a number of projects to support the 'liberal' and universal image of the regime, and especially that of the popular Prime Minister. Health and well-being were identified as goals that would appeal to practically everyone. Among the various catchy slogans distributed for consumption to the general public, one was, *Sab ka Saath, Sabka Vikas* — meaning, 'we want everyone to work together for everyone's development'; another was, *Banega Swasth India* — meaning 'India will become healthy'. A strongly projected slogan — *Swatch Bharat Abhiyan* ('The Clean India Campaign') — was launched with great intensity but the actual policies and their implementation fell short of such intensity. The main spanners in the implementation were inequality and poverty, lack of infrastructural facilities and poor distribution.

At the beginning of the pandemic, in February 2020, India was among those nations that quickly announced a lockdown, even before the cases had crossed into three figures. However, no attention was paid to the marginal, the poor, the daily wage workers, the cab drivers, the pavement-sellers, the migrant labour and those employed informally in the places that were shut down, like shops and restaurants, malls and gyms. The first phase was marked more by the sufferings caused by the lockdown than by the disease itself (Channa 2020). Globally, the visuals of hundreds of people walking on foot in the heat and dust of the Indian summer, trying to get back home, went viral in all media. At that time, the migrant issue was the real issue — much more serious than the virus. It is reported that more than 8,000 migrant workers, desperate to get home were mowed down by trains, as they walked along the train tracks so as not to lose their way during the hundred-of-miles trek to their villages. These were workers who had come to Delhi to earn a living from far flung less prosperous, areas with very little resources as compared to the city.

Elsewhere (Channa 2019), I have discussed under what conditions, the poor and the marginal are forced to leave their villages and small towns and migrate to the cities. The fate of these workers during the pandemic highlighted a blind spot in the vision of the state about those that do not belong to the formal organised sector of the economy, those who exist on the fringes without any rights. At this juncture, it was civil society more than the state that came to the rescue. The state responded by passing formal laws such as that prescribing that no one could be evicted from their premises during the lockdown or that prescribing that employers must pay wages; but there was no way to implement these laws, especially at the lowest level. The failure of the state to protect the interests of the most vulnerable is also linked to the limited capacity of such people for political action. Thousands of people faced death due to starvation, fatigue and accidents on the roads, but they went without protest.

However, it was the deadly second phase of the pandemic, caused by the regimes' self-assertion and tendency to take credit for its 'stupendous work' during the first phase, that shook the faith of the people. Questions were raised about the legitimacy of the state, asking how it could make such monumental blunders. It is reported that between January 2021 and February 2021, India exported through donation and sale 60 million doses of the indigenously produced vaccines and gifted and otherwise distributed life-saving medicines to needy countries, notably its neighbours. But by March 2021, there was a complete turnaround of events. India developed a double mutant variety of the virus, now named 'Delta'. April 2021 saw numerous deaths caused by lack of oxygen supply in the city's premier hospitals; at times 50 to 60 patients died at the same time, as oxygen supply ran dry. It was in this period that I lost my only sister and a number of other family members and friends to the pandemic.

Hospitals had to shut their gates due to lack of beds and people died while waiting in ambulances or just waiting in their cars or on the roads. The rush at the cremation grounds was such that bodies had to queue up for disposal, the wait time stretching to 12 hours, at times. There were shocking stories that large numbers of bodies had been thrown into the river Ganga[1] by desperate relatives who could not afford to cremate them as price of all materials required for death rituals had begun to sky rocket. In other words, things had descended into chaos. This shook up the power lobby at the centre, and after the initial euphoria of having successfully dealt with the virus, there was silence for a while from the centre.

The disillusionment with the ruling regime was demonstrated by the BJP losing elections in several states where they were held in April 2020, at the peak of the pandemic. A miffed power centre became reluctant to help the states where it had lost power, as a political vendetta leading to further resentment. Fingers were also raised at the power centre for focusing attention on election campaigns and not putting a curb on the Kumbh Mela, a major Hindu festival held on the banks of the river Ganga at Haridwar. Both these actions were seen as related to the political aspirations of the powerholders with little regard for people's health.

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[1] Throwing dead bodies into the Ganga, when proper rituals cannot be performed is an age-old practice, as the river, considered as a goddess, is supposed to purify anything that is thrown in it. People float the dead bodies of their relatives in the Ganga, in the hope that they will attain salvation.

The Kumbh Mela was in fact shut down only when several major religious leaders became infected with the virus. Citing situational contingency, the religious leaders left the Kumbh Mela as the right thing to do at the right time. But by then a lot of damage had been done and, as the people returned to their villages and towns, they brought back the virus with them. Yet, there was no blame at this time. Unlike the demonization of the event organized by the Tablighi Jamaat — a Muslim movement — where about 3,000 people had congregated in March 2020, an assembly of a 150,000 people performing rituals and bathing on the banks of the river with practically no precautions was not proclaimed as a super spreader; in fact, most news channels and media kept a total silence over the issue. The Islamic congregation had been widely condemned during the first phase of the pandemic.

With chaos and suffering everywhere, people had no other enemy to turn to, except the state. The anger was mostly directed towards the centre, for breach of promises, the inability to assess the future of the virus and for ignoring advice from knowledgeable sources. The head of the virology advisory committee resigned on the grounds that his repeated advice was ignored by those making decisions. This resignation was not broadcast by most of the Indian media; a few stations broadcast this news on international television only. Instead of trying to mitigate the situation, the government engaged in a game of covering up and reverse propaganda (*The Statesman*, June 2021) in an attempt to put the blame on the states, especially where there was a non-BJP government. But much of this misfired.

By January 2021, India had its own indigenously-manufactured vaccine, yet miscalculations by the centre cost a large number of people their lives. This particular lack of judgment on part of the leaders, brought down their legitimacy in the eyes of the people. According to the Hindu worldview, the ruler is like a parent to his/her people. Rulers should care for the lives and welfare of the people who depend on them. A serious breach of this principle occurred when the state decided to earn a name for itself internationally; that is, when it allowed large amounts of resources, much needed in the country itself, to move to the outside. This is one key instance where trust was lost, as so many people were hit where it hurt the most, the loss of loved ones.

To Conclude: How Legitimate is the Present Regime? And for Whom?

In several essays, Pardo (e.g., 2012) argues that legitimacy has a dynamic nature and cannot be separated from the ongoing social processes of which it is only a part or a reflection. Prior to the pandemic, the right-wing BJP government had staked its legitimacy on the basis of ‘faith’ over ‘rationality’ and of religion above equalitarianism. It advocated both upper caste supremacy and patriarchy, under the garb of following Hindu dharma and a Hindu nationalism based on identity and self-pride. It managed to disguise its partisan attitude by showcasing paradigms such as ‘development’ and removal of corruption. However, although apparently very transparent and rational, these transformations hit, and were probably meant to hit, the poor and the marginal. The state was obviously driven by a corporate and pro-upper-class agenda disguised under progress, development and the removal of corruption.

With the pandemic, the scenario changed considerably. The virus cut across caste, class, religion and all other social divisions; so, it became impossible to have a hidden agenda that would be pro-upper caste and class and also be effective in controlling the pandemic. Although in the first phase there were attempts to shift the blame on the category of 'others'; such as Muslims, such machinations failed completely when the pandemic hit a peak and affected a very large proportion of the population. It was no longer something that happens to others, it was something that was happening to practically every one, very close to their own bodies and those of their loved ones. Legitimacy could not be derived from ideological rhetoric or from empty signifiers, people were expecting concrete action.

The OECD has identified four major parameters for identifying the legitimacy of a state (Pardo and Prato 2019: 2). The third is 'shared beliefs', it presumes common beliefs, religion and charismatic leadership as leading to a 'shared political community' of the ruler and ruled, which is problematic in a widely differentiated and plural society like India. Here, several religions co-exist, and there are numerous sub-divisions in the major Hindu religion, which also professes that all paths lead to the same truth. There is also a globalized, cosmopolitan and liberal civil society that stakes claim to common humanitarianism and seeks legitimacy to rule by performative characters and adherence to legal norms. This section of Indian society also invokes a humanitarian and inclusive version of Hinduism. Importantly, the textual religious ideology that is the backbone of the right-wing regime invokes the ideal ruler as just, equalitarian and responsible. The failure ultimately to protect the people against the pandemic was seen as a loss of legitimacy to rule, both in terms of a rational-legal model of instrumentality and a model of ideal ruler as derived from the sacred texts of Hinduism.

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Managing Public Health in a Fragile Consociation: Lebanon between Wars, Explosions and the Covid-19 Pandemic

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Shortly after the 2006 Hezbollah-Israel war, I organized fundraisers at Kent University in the U.K. — then my employer — and in my hometown of Sicily. Back then, I enjoyed frequent exchanges with the people in a Christian enclave bordering Israel with whom I resided during that war (Mollica 2014a). I received a receipt and a letter of gratitude in acknowledgement of the money transfers that I had made to the municipality. The receipt detailed all the municipally-purchased medicines from a pharmacy of a nearby town. During the war, gathering medicines was a major problem. Indeed, one of the last photographs I took just before my evacuation was of the then deputy mayor, who was drafting a list of medicines that were needed in the village. He then organized a car trip to a nearby village where there was a pharmacy, of course having alerted Unifil (United Nations Interim Forces in Lebanon), the Idf (Israeli Defense Forces) and Hezbollah.

The journey of that (Christian) car was emblematic of a fractured country. It was a mirror of a sectarianism that not even the war had managed to appease. Although during the war Christian and Shia communities — the most affected by the conflict — were helped not only by their co-religious but also by other communities, the municipalities remained divided by religious affiliation which changed topographically as the villages changed, including what was within their borders: a pharmacy in a Shia village remained nominally Shia, and a butchery in a Sunni area remained nominally Sunni. The fact that these settings were attended also by other communities did not diminish their religious affiliation, which went far beyond the divisions codified by the legacies of the personal statutes, penetrating every domain of social life.

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Italo Pardo (2004) has showed how the largest modern Italian scandal, ‘tangentopoli’, originated in an inquiry on corruption in public life that produced the arrest of a businessman who worked in the health service. The businessman justified his behaviour by saying that in order to survive he adopted the normal way of doing things. Building upon this case, Pardo suggests that when there are no alternatives, ‘people may treat certain illegitimate […] acts as unavoidable evils’ (Pardo 2004: 37). Meanwhile, ‘wrongdoings that may not […] be legally defined as corrupt [are] condoned’ (ibidem). His Naples ethnography addressed the relationship between patients, people and institutions deemed to provide health services. He reached two conclusions: firstly, the health service was considered extremely important; secondly, the dynamics of corruption were articulated on two interlinked levels: on the one hand, the patient/carer and, on the other hand, the local institutions of the health service (Pardo 2004: 37-38). In order to obtain a favour, it is not necessary to make payments of money or some sort of ‘direct profit’ — the process is part of a ‘generalized mode of exchange’ (Pardo 2004: 40). For instance, a common practice was to have doctors ready to certify ‘non-existent-illness in exchange for money’ in order to obtain votes (Pardo 2004: 41). Polese

(2014) shows that monetary payments in Ukrainian hospitals traversed several levels between gifts and bribes, depending on whether those payments were made after the provision of health services or as a pre-requisite to obtaining healthcare. The exchange of money/gifts in the healthcare sector does not necessarily imply the prevalence of corrupt practices. The degree to which these gifts/payments become a barrier to obtaining health services classifies the system as corrupt.

Similar dynamics can be found in Lebanon, where the relationship between patients and doctors and with health provider institutions is regularly based upon informal relations. In my fieldwork, I came across stories of votes exchanged for support. Illustrating this point, Cammet (2014) shows that activists for a political party ensure greater access to finance for healthcare than non-politically-affiliated individuals. Political parties broker access to healthcare by interceding on behalf of their supporters with the minister of public health, with the syndicate of pharmacists and doctors and with privately-owned clinics and hospitals. This brokerage of healthcare services can increase the degree of intra-sectarian party competition. For instance, some Christian political parties stepped up their inter-party competition for the loyalty of supporters in their constituencies by building a mutual fund programme whereby subscribers gain access to healthcare and private insurance schemes at discounted prices (Cammet 2014, Helou 2020).

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Pardo argues also that ‘we need to understand, with Weber, that the authority to rule depends on recognition of rulers’ legitimacy across society’ (Pardo 2000 quoted in Pardo and Prato 2019: 1-2) and that legitimacy’s ‘contours may change over time alongside changes in people’s values and moral expectations’ (Pardo 2019: 3). In such a frame, ‘political and governmental bodies that fail to respond to the instances of citizenship [contributes] to widening the distance between rulers and the ruled’ (Pardo and Prato 2019: 5-6). In turn, ‘when rulers lose legitimacy […] their power’ (Pardo and Prato 2019: 6) becomes authoritarian. This is virulent in democratic societies (ibidem), but is manifested also in the Lebanese context, above all during the incumbent Covid-19 pandemic.

The history of modern Lebanon has long been marked by tensions among and within the religious sects that hold a share of power and the overarching national structures. This follows a model based upon religious affiliations, not on normal democratic electoral rules. Such a model has taken a sectarian path that takes into consideration transnational loyalties which, at times, are stronger than national loyalties. The tension is proportional to the way in which foreign money is, first, internally allocated and, then, legitimized. This was the case with the tension that followed the support that Lebanese communities received after the 2006 War (Mollica 2014b). More recently, it has been the case with the rhetoric around the introduction of Covid-19 vaccines.

This tension is apparent in South Lebanon, where Hezbollah’s post-conflict strategies of reconstruction have been legitimated (Mollica 2010, 2014b). These strategies have eroded the rule of law and its interpretation (Mollica 2019). But this also seems to be the case with the reaction of Lebanese diasporic communities to the explosion of the summer 2020 in Beirut. This process becomes visible when communal loyalties overcome individual needs, thus bypassing state legal codes (Mollica 2019). Given the perceived absence of the state, formally illegal customary actions are regarded as legitimate, as the sectarian reactions to the pandemic has recently proved

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Since 2006, I have collected data on Lebanon and have periodically discussed the unfolding events with my informants. Now, due to the Lebanese government-imposed Covid-19 restrictions and the resultant difficulties in doing fieldwork, we speak via Skype. Recently, we have re-discussed the aforementioned 16-year-old photograph in light of the last Lebanese events. That photograph was taken at the beginning of the third week of the war. A few days later, the situation worsened. Following the closure of the village's bakery, local authorities had to ration bread as it was difficult to go to the Shia village of Naqoura. The supplies of medicines also became scarce. Then, the locals were told to go north of the Litani River to get medicine, which was an impossible journey because the Idf bombed all the bridges. The relatives of local people who resided in Beirut and some NGOs sent medicines, which remained trapped north of the Litani and reached the village only a week later.

Having commented on that photograph and heard my explanation of my new research project, the former deputy mayor shared with me his doubts about the way the Lebanon was reacting to the pandemic. He said:

> 'In 2006, we had a government, we had money, people could buy medicines. Today, because of the corruption, we have no money, nobody can help' (former deputy mayor, June 2021, Skype videocall; henceforth fvm).

He was critical about the political vacuum in Lebanon. He thought that the situation was worse than during the 2006 war, for then at least there was a government. In terms of responsibility, external factors emerged, matching a long-lasting narrative. He blamed other countries because they were not helping Lebanon.

> 'My friends are dying because they have no oxygen machines. What are the big countries doing, we need them to bring medicines to the Lebanese people via *their* [italics added] NGOs?' (fvm).

He claimed that major countries were punishing the Lebanese people who were trying to hold their politicians accountable. Indeed, a number of Lebanese politicians are involved in major scandals and are placed on the black lists of several Western states. On a local level, the incompetence of the political élite has had a devastating impact.

> 'The black market is everywhere; it is a jungle. Even if vaccinations are now getting somehow available, people get drunk and use drugs' (fvm).

Sectarianism is as present as before, above all in decentralized areas where the consociational construction meets real life. There, sectarian dynamics are at work and local customs are deemed stronger than the national law. What happened with the vaccine distribution in South Lebanon is a case in point. As the deputy mayor said:

> 'In a South Lebanese Sunni village, not far from my village, the locals got 1000 doses of vaccine without any registration'.

This happened because a Sunni political leader helped them. Other Christian informants I spoke to also pointed out that even Shia and Druze leadership helped their communities with the vaccinations, bypassing state delays. This, however, was not the case for most Christian communities. This problem was linked with other problems, such as endemic power-cuts, lack of medical supplies, rising of poverty, shortage of water, increasing difficulties with internet access and education being often out of reach. Finally, this overlaps with the belief that the currency reserves kept in the country's Central Bank are at a critical level.

When considering the contemporary political management of public health, it is important to contextualize the events. As a colleague from Beirut has recently suggested, the issue is rooted in three factors: 1) the ability of the Lebanese Government to govern; 2) geopolitical interests and regional shifts; 3) communal reactions. After the 17 October 2019 Revolution, it became clear to many that there were no 'Lebanese people', but 'different sects'. Since then, political élites started playing a critical role. At the same time, people's disaffection towards the élite grew.

* * *

Most important, no persuasive verdict relating to Prime Minister Rafiq Hariri's assassination (14 February 2005) was issued. Hezbollah gained popularity among many Lebanese communities and several international actors following the July 2006 war, but this popularity diminished following Hezbollah's potential complicity in the Hariri assassination. Hezbollah rejected the establishment of an international Special Tribunal for Lebanon to try the perpetrators of the Hariri assassination and withdrew from the Government. As a spill-over effect, frictions entered the regional arena. The Doha agreement of 22 May 2008 was marked by a political consensus, following Hezbollah's 7 May 2008 invasion of Beirut. The subsequent round of National elections in 2009 proved to be the most expensive Lebanese elections. Money was channelled into Lebanon, which was followed across the country by an increase in the private Hezbollah institutions; that is, hospitals and clinics (Mollica 2014b).

The 2011 Arab Spring and the associated regional shifts brought about changes in Lebanon. Egypt's regime change and the Syrian War affected the regional power balances. Initially, money flew into Lebanon, as Hezbollah participated in the Syrian conflict (Panchetti and Mollica 2019). The Lebanese Central Bank seemed capable of managing finances. However, since 2011, Lebanon's balance of payments became consistently negative (Helou 2021, 2022). The involvement of Hezbollah in the war reduced the entry of money into Lebanon. Iran did not invest in Lebanon as before, but started investing directly in Syria. Even for the Arab countries Lebanon was no longer a priority. Since 2015, the economic situation has worsened. In the summer of 2019, a growing gap between the official exchange rate of the Lebanese Lira to the Dollar started taking shape (Helou 2021, 2022). The 17 October 2019 Revolution occurred with the persistent imposition of flat taxes — triggered by a proposal of a $6 monthly tax on Whatsapp calls — as opposed to progressive taxation. Unsustainable national debt, dwindling foreign currency reserves in the central bank, a consistent negative balance of trade as of 1990 and a set of distorted public finance policies exacerbated an already difficult situation (ibid). For the first-time, people organized themselves in a bottom-up non-sectarian way. A rise of socio-economic demands ensued. Then, the Covid-19 pandemic struck. By 7 March 2020, the Government defaulted on its sovereign debt payments, declaring insolvency. Depositors could no longer withdraw their U.S. Dollars from their accounts, but certain amounts in Dollars became denominated in Lebanese Liras, thereby implementing an unspoken haircut on deposits and unspoken capital controls (Helou 2021, 2022).

These processes had a significant impact on the health sector. The pandemic hit Lebanon fast. It took two weeks from the detection of the first Covid-19 case for a lockdown to be imposed to. Still, at the start of the pandemic things were somehow under control. Hospitals could get medicines and the Central Bank could transfer money for medications. But hospitals were calling for the state to help pay debts. Normally, in Lebanon, hospitals admit patients with the following health plans: 1. the National Social Security Fund; 2. patients' coverage from the Ministry of Public Health; 3. private health insurance. Once the situation got worse, private hospitals stopped admitting patients under the first two health plans.

Everything, from gasoline to clothing and hospitalization, was impacted by the rise of the U.S. Dollar. This happened because 90% of Lebanese consumption was based on import and Lebanon could no longer use its dwindling Dollar reserves; so, the Central Bank stopped spending money on essential items. In 2020, all prices rose again in Lebanon, following tourist arrivals. On Christmas 2020, political authorities opened up the country because Lebanon needed money. But then another lockdown was imposed.

Meanwhile, on 4 August 2020, another dramatic event had taken place: Beirut port explosion. It was quantified as the largest non-nuclear explosion in the history of the planet. The explosion was followed by a new wave of international support. As a colleague from a Lebanese university, pointed out:

> 'Despite the damaged area being mainly Christian, casualties were from all communities; and this impacted everyone. A lot of money flew into the country; political parties tried to get money; the diaspora got involved again'.

Everyone felt impacted because casualties affected all sects. However, the position of some political parties about the explosion was ambiguous. As the same informant pointed out referring to a long-established situation,

> 'it was the fragmentation of the system that had to be blamed for the explosion, because nobody knows who allowed the chemicals to be stored there; there are no memos about that while three different ministers, belonging to different political parties, held their positions since the chemicals were stored there.'

Following the explosion, international attention returned to Lebanon and mobilization resumed. Local people and students helped with the relief effort. The emotional support intensified. However, after a few months the country moved back to what some informants called a 'state of chaos'.

* * *

The chaos increased the fragmentation. Communities polarized again opening the door to the old sectarian narrative to which the ambiguous attitudes of the élites added. These ambiguities built upon what an informant called the 'sectarian mind'. On a different level, at one point during the pandemic, the Maronite Patriarch asked his priests in Lebanon to stop praying in churches. Some

Christians replied that Muslims were still praying in their Mosques, which reflected the need for policies that establish sectarian parity in the practices. However, the Secretary General of the Shia party of Hezbollah, Hassan Nasrallah, explicitly stated that he wanted Hezbollah supporters to consider the fight against Covid-19 as a Jihad. He asked people to avoid public gatherings that included rituals, funerals and other religious processions.

The relationship between religious practices and the management of health was also an intra-denominational problem. A key challenge for the Maronite church pertained to the Communion during religious service. The Maronite patriarch granted permission for the faithful to receive the Eucharist from clergymen during service and then self-administer the Communion, to minimize the risk of infections. Some Maronite clergymen refused these newly-proposed measures on the ground that they violated the sanctity of the Communion.

* * *

One of the most interesting scenes of the film *Under the Bombs* (2007), shot in the wake of Idf bombardment of South Lebanon, is that of a taxi-driver approaching an NGO ship in the port of Sidon. The ship is unloading medicine and the man tries to convince one of the workers to give him some medicines, claiming that they are for a sick relative. He was lying, and we can guess what he could have done if the cooperant had given him the medicines. This scene came to my mind when an informant told me that the Government had no money left, not even to buy masks to distribute to workers in vital sectors.

In my last interview with the former deputy mayor, he raised the issue of vaccines being distributed according to sectarian lines. Once vaccines became available, Lebanese politicians tried to get them, to distribute in their constituencies. The Sinovac vaccine entered the country via Hezbollah; Sputnik entered the Beqaa through a local politician. Moreover, China offered 150,000 doses of Sinovac to the Lebanese Army. The idea of donors was however magnified through a consortium of universities. One of them, the Lebanese American University (LAU), received a donation of a million dollar from Bahaa Hariri to buy Pfizer vaccines through the Lebanese government for its faculty, staff and students.

The impact of Covid-19 has deepened the Lebanese chasms. The international extensions of the local factions added to the fragmented nature of the Lebanese political identity. This exacerbated the role of religion in the management of public health, while the management of the pandemic threatened the fragile Lebanese system. Narratives and ambiguities widened then the gap between religious groups and between them and the central government. Fitting a tradition of sectarianism, the pandemic enhanced the tensions which traditionally have become more manifest at times of crisis.

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Interrogating the Public Health Approach: Lessons from the Field of Urban Violence

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Governmental responses to the COVID-19 pandemic have brought public health discourse to the fore in societies around the world. The public health idiom had already made serious inroads into understandings of, and attempts to address, urban violence (particularly among young men). With COVID-19 almost inevitably becoming ‘endemic’, the role of public health discourse will only become further entrenched and extend to the analysis of a wider range of societal ‘ills’ (not all of which are directly connected with COVID-19 and other Corona viruses). This article seeks to analyse the application of the public health approach to attempts to address urban violence using fieldwork conducted in London. As explained more fully below, the fieldwork was carried out in a number of settings across the English capital, between 2009 and 2018. We are especially interested in interrogating the public health model on its own terms. For example: What is the disease? How are symptoms identified and gauged? Who are the victims? How is the ‘cure’ formulated and administered? And how is recovery from the social ill of urban violence captured and calibrated? More prosaically, while we know about some of the theoretical-conceptual implications of viewing urban violence through a public health frame (Riemann 2019), we know less about how these implications play out in the everyday settings wherein agencies are expected to work together to combat urban violence.

In exploring these issues, we combine the findings of our own fieldwork with the growing literature on the application of public health approaches to urban crime, as well as scholarly debate around trust and authority in the context of legitimacy (Pardo and Prato 2019; Pardo and Prato eds 2019a, 2019b). This allows us to examine the institutional and personal tensions that exist in the context of public health-inspired, multi-agency work on addressing urban violence, as well as wider political and ideological assemblages. We also pause to make comparisons with other approaches to violence, including some alternative methods of addressing urban violence, and question whether Agamben’s assertion about the imposition of a ‘continuous state of emergency’ – discussed recently by Prato (2020) — is relevant in the case of urban violence and public health. Here links can be drawn with Marcello Mollica’s analysis of war and public health in Lebanon (2022). While in the latter context questions about public health are posed in the context of full-scale civil war, in the UK violent territorial disputes among youth groups have been used to create something approximating to a state of emergency wherein public health interventions (which implicitly endorse the prevailing neoliberal logic of the UK government) can be easily justified.

Although the broader research was conducted between 2009 and 2018 across a number of London boroughs, the lion-share of the fieldwork took place in the London Borough of Newham (LBN) between 2011 and 2012 and was part of a wider project which sought to examine the policing of the 2012 Olympic Games (Armstrong et al. 2016). As acknowledged later in this discussion, a large part of the policing and security planning around the 2012 Olympic Games pertained to the issue of gangs and Serious Youth Violence (SYV) in East London (and especially LBN). While the threat of a large-scale terrorist attack was certainly among the concerns of the upper echelons of the Metropolitan Police Service (MPS), at the level of everyday policing it was skirmishes over the territory of street gangs and the extension of this territory into freshly minted Olympic and commercial spaces that dominated. Policing and security preparations for the Games coincided with the introduction of gang databases in London. These databases were pioneered in the United States and aimed to identify an area's key gang members as well as rate them algorithmically in terms of their violent potential (Fraser et al. 2019). The database used in London is called the Gangs Matrix and has been at the centre of serious controversy over racial disproportionality plus possible contravention of human rights and data protection legislation (Amnesty International 2018). Early use of the Gangs Matrix in LBN went with the grain of public health approach with regard to risk, harm and contagion. But there were problems. As we will show, the wider approach to addressing youth violence was poorly articulated, with the Gangs Matrix integrated into existing policing and security strategies rather than representing anything substantively new.

The pursuit of being predictive in the Criminal Justice System (CJS) is inspired by the non-retributive penal philosophies of prevention and reformation. Any sentence passed on the convicted is implicitly a failure of prediction and thus considered by many as a significant task in creating a predictive assessment of future behaviour. How the suppositions of predicted future behaviour should be delivered and by whom is a crucial consideration for criminology, not least because prediction has to be considered from an *individual* perspective (is the offence an outcome of individual anomie?) and an *institutional* perspective (how many prison places might there be?) and indeed from a *categorical* perspective. In this latter consideration, we need ask whether a number of individuals are appearing in the CJS by virtue of a lifestyle wherein practices and stigma precede individual circumstances (Mannheim and Wilkins 1955).

Predictive studies were explored close to a century ago by Burgess (1928) who examined 3000 parole records of imprisoned male offenders in Illinois State penitentiary and, in considering 21 factors, attempted to establish a points system of predictability. There was no follow-up research or weighting system and the only resource the researcher had to draw on was the official parole documents. Around the same time, the *Guess Who? Game* pioneered by Hartshorne and May (1928) took 4520 school children aged between 8-13 and, using vaguely derogatory statements, asked them who in their class fitted such epithets — a technique supplemented by IQ testing. Later, Glueck and Glueck (1930) sought information about offenders beyond that compiled by CJS officials, reducing the factors to six and extending the prediction timeline to 15 years (beginning from the age of six), as they compared 500 delinquents with non-delinquents based on subjective ratings. The study's sample was not random; all offenders were drawn from a reformed school and had long criminal histories. Crucial to the metric were considerations of family, traits derived from the Rorschach Test and characteristics deduced via psychiatric interviews. Mannheim and Wilkins (1953) took an approach similar to the Gluecks but, utilising a more sophisticated statistical technique, attempted to deal with those considered ‘un-predictables’ (those on the borderline of probable success and probable failure).

Any attempt at predictive profiling thus has issues. At one level, it is about the idiographic and actuarial nature of the proposed intervention; is early intervention worthwhile? Is all behaviour treatable? Then arises the issue of validation; namely, what intervention is proven? In 1951 Cambridge University academics conducted the Somerville Experiment which, via an elaborate interview procedure, ranked male juvenile offenders on an 11-point scale. This was more successful than the merely impressionistic assessment of their schoolteachers in predicting future offending. In 1952 in the Journal of CLCPS Hathaway and MCkinley (1942) attempted to utilise the MMPI for predicting delinquency but with little success. Around the same time, the California Youth Authority pioneered the Jesness Inventory which sampled 145 delinquents and 300 non-delinquents on a 155-point scale which sought a true/false response around the themes of social maladjustment, alienation, anxiety repression and withdrawal to produce an ‘asocial index’ to identify 74% of delinquent behaviours.

Scales have interested those seeking predictions. One such was the 1963 *Bristol Social Adjustment Guide* which via its researcher D.H. Stott at Glasgow University measured a child’s social adjustment and developed a delinquency-prediction scale and claimed a high correlation over the 15-month duration of the research. The Milligan Scale was a long-term follow up study of 5000 children begun in 1958. This provided some predictive value as it correlated incidents of childhood aggression with later delinquency. The Rutter scale is still being utilised and Havinghurst et al.’s (1962) longitudinal study of 5000 11-year-olds provided socio-metric testing for ‘maladjustment’, ‘aggression’ and ‘withdrawal’. Interestingly, very few of the research cohort turned out to be delinquent.

Kvaraceus’ (1953) checklist itemised 75 items of personality which included home background and schooling but was never really used as a predictive device. The California Psychological Inventory (CPI) produced by Gough (1956) contained a ‘socialisation scale’ which sought to measure ‘degrees of social maturity’ and probity that an individual could be argued to have attained and was utilised later by Dinitz, Scarpitti and Reckless (1962) to study youth offenders in HDAs. The latter author then developed the Self Concept scale, asking how much the subject saw oneself as an influencer (the respondents were chosen by schoolteachers). We might also consider Rosenberg’s (1965) exploration of adolescence which used self-concept variables to develop a series of scales around adolescence.

Crucial to daily policing, the issues around intelligence are three-fold: how is it gathered, who collates the sources of information and how is such information then utilised? Also critical are the systems of storage, co-ordination and dissemination, alongside intelligence-sharing protocols. We might add a few further considerations when addressing intelligence, namely: What reaction timelines are ideal for information received? Who completes the profile of the individual offender? From whom is the information drawn and how reliable is it? To whom is the information communicated and for what purpose?

Our fieldwork was conducted across four London boroughs. In this article we use the findings of interviews with practitioners in each of these locations. The practitioners were principally drawn from multi-agency teams which included police, Youth Offending Services, plus representatives from education, probation, and various third sector workers. By 2017 (when this bout of fieldwork began), the public health approach was being articulated more fully and implemented more comprehensively. While the Gangs Matrix remained at the centre of data-driven operations and interventions, these were formulated and effected in the context of a multi-agency team and principally geared to prevention and safeguarding (with enforcement a last resort). That said, while there were differences in approach across the two bouts of fieldwork, a common factor across all settings was an austere financial climate wherein resources were sparse. Issues of funding, staffing and wider questions around capacity evidently affected practitioners' ability to implement the public health approach as well as their views on its advantages and disadvantages.

The fieldwork itself comprised observation of police and multi-agency meetings and operations plus interviews with a range of police, local authority and third sector practitioners. In what follows we use a combination of fieldnotes and interview excerpts to interrogate each element of the public health model — from diagnosis to treatment and claims about recovery — with the analysis section of the paper organised accordingly.

In the analysis section we present the lessons learned from this multi-sited ethnography of public-health-inspired approaches to address (or 'cure') urban violence. While one may assume that programmes formulated and implemented in the name of public health can be separated from questions of politics and legitimacy, our findings demonstrate that this certainly is not the case. We need only consider varying responses to the COVID-19 pandemic to acknowledge that public health programmes overseen by national governments have been intrinsically (and in some cases, emphatically) political, with the legitimacy of each programme relying on appeals to wider notions of common sense (themselves underpinned by ideological motifs such as 'individual responsibility').

It should come as no surprise, then, that the application of public health programmes in the area of urban violence is fraught with questions about legitimacy and wider political values and imperatives (Rosbrook-Thompson 2019). Many of the people we interviewed and observed were sceptical about the ability of the approach to address the real causes of the 'illness' in question. The implementation of data-driven public health models also had unintended operational consequences, in some cases intensifying the effects of staff shortages. However, even where there was significant scepticism around the model and the gang databases at its core, police and practitioners were encouraged to frame their own knowledge and intelligence according to the conventions of the Matrix which, while effective in securing extra resources, resulted in inaccuracies that could be costly for the young people involved. Inevitably this led to the misidentification of gang members, with pressure exerted by Gangs Command to meet certain quotas when peopling the Matrix. This reflected and fed into wider anxieties around racism and racial disproportionality, with some practitioners being critical of the medical model's pathologizing of particular communities. In describing this dynamic, we reflect on what critical scholars of science and technology have argued about the performativity of statistics, algorithms, graphs and formulas.

The treatment administered through the form of evidence-based interventions was similarly open to considerations regarding legitimacy. There was concern that the seemingly systematic and sophisticated approach to identifying and gauging the symptoms of urban violence was unmatched by the nature of multi-agency interventions. Indeed, for some respondents the need to secure wider legitimacy for the Matrix — and the day-to-day work this entailed — actively hampered the ability to intervene quickly and effectively. The inputting of data was very time-consuming as was the hardening of 'soft' intel in the interests of accessing greater operational resources. Such reifying of 'soft' intel — in the interests of meeting short-term objectives — has led to a significant crisis of legitimacy for the Gangs Matrix spearheaded by the Information Commissioner's Office (2019) and the charity Amnesty International (2018). Also — and perhaps inevitably — the institutional allegiances of individual team members shaped their perceptions of the legitimacy of the public health model.

These (sometimes divergent) institutional concerns were present in discussions of recovery and questions as to how to measure success. For some, objectives were relatively modest; and this was consistent with the way that their employer calibrated success (and failure). For others, especially those closest to ongoing discussions about costs and funding, only headline figures such as annual statistics on SYV could demonstrate success. What united most respondents was a belief that the model could *demonstrate* success.

In conclusion, we note how the analysis of this issue takes us back to Pardo's (1995, 1996) and Pardo and Prato's (eds 2019a, eds 2019b) claims about notions of democracy, citizenship and the legitimacy of rule perpetuated by governments who are interested in protecting the interests of the privileged, even at the cost of those at the bottom of the social hierarchy. We also examine the current climate surrounding public health discourse and, inspired by Judy Arnold's analysis of the legitimacy of the medical establishment in the USA (2022), ponder whether the crisis of legitimacy surrounding UK government's handling of COVID-19 pandemic will lead to a more widespread questioning of public health discourse. Finally, there is the possibility of the targets of public health interventions themselves seeking to resist their identification as a 'health problem'. This may see them question the suitability of the health approach in the name of something like Elizabeth A. Olson's 'health sovereignty' (Forthcoming), or even question the UK government's very notion of 'access' to healthcare (Prato 2022).

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Crisis, Rupture and Legitimacy: Final Reflections

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At this writing, the anniversary of the January 6th, 2021 riot at the US Capitol approaches. On that day an angry mob of armed extremists (or ‘mobsters’) stormed the Capitol building in a desperate bid to prevent Joe Biden from becoming President and to return Donald Trump to the White House. In so doing, the rioters intended to Stop the Steal, and thus to correct what they regarded as a grave miscarriage of justice. In re-instating Trump, however, the mobsters sought to do more than right a single wrong. They also had broader, more all-encompassing goals. In their view, the election was a sham, the results having been wildly distorted by systematic, widespread fraud. The idea that dark forces would attempt to perpetrate such a fraud upon the American people was deeply troubling. More disturbing still, however, was that they had succeeded. The debacle of the election, the mobsters believed, revealed the presence of dangers so ominous that they threatened the country at its very core. Returning Trump to the presidency, they hoped, would stem the tide of those dark forces.

These views are extreme but not at all unusual. Although once restricted to the margins of political life they have come to occupy its very centre. Indeed, such views are now shared by millions upon millions of like-minded individuals, all across the country. Despite their open and explicit xenophobia and intolerance, these individuals regard themselves as making up a ‘moral community’. Symptomatic of the fear and fervour that drives this community is the following: although the January 6th mobsters killed and maimed, and although they sought to do far more (they intended to hang the Vice President of the US in a public execution), neither the mobsters nor the moral community view the events at the Capitol as in any way problematic. To the contrary: they view the mobsters as patriots and the January 6th Riot as part of a revolution.

America’s new mobster/patriots believe that the violence of January 6th is legitimized and sacralised by a calling higher than the law. They regard themselves as the last line of defence in a battle with profoundly malevolent forces that have already infected the country with impurities, and now threaten it with imminent demise. What is at stake in this struggle is not just the deaths of a few individuals (at the Capitol) but the death of an entire nation, an entire people. Indeed, America’s community of mobster/patriots believes that the US has fallen from a great height. Tragically, a way of life that was once the envy of the world is now crumbling. That way of life *must* be protected, at any and all cost.

The mobster/patriots were certain that the fate of Donald Trump would determine the fate of their country and, as January 6th approached, they became increasingly fearful. Convinced that America nation was in dire need of assistance, and having exhausted all legal channels, the mobster/patriots took up arms to answer that need. January 6th, however, was just the tip of the iceberg. Indeed, the moral community that has formed around Trump — a community based on suspicion and xenophobia — seeks to spearhead a sweeping movement of purification and re-birth that is akin to a Holy War, and is being waged against an entire host of enemies. This war is intended to restore the health and wellbeing of a society that is ridden with disease and poisoned by contaminants. Among the most striking features of this war is the following: those fighting it regard as their sworn enemies not just the usual suspects (minorities, feminists, foreigners, liberals) but virtually the entire state apparatus. Indeed, the patriots who have come together to preserve their endangered way of life believe that the state has completely discredited itself. At a result, only patriots (mobsters) can be trusted to exercise armed force in defence of the country's legitimate citizens.

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The events of January 6th are a useful point of entry into the issues that are explored with such skill, insight and originality in the contributions to this Special Issue. The authors document in rich detail the emergence of new communities of suspicion (and trust!) all around the world. They document as well the fierce struggles that rage over the meaning of the public, and how to safeguard the health of the public. The essays bring to light equally contentious debates over the parameters of the citizenry, over who may act in its name, and what it means to do so. The articles document case after case in which the state is seen as having failed the general populace. Indeed, the authors show that in a great many contexts, legitimacy is no longer regarded as residing in the institutions of government. Rather, it is seen has having migrated elsewhere, to diverse non-state locations. In these locales, alternative forms of legitimacy and community are unfolding.

In broaching these topics, the studies in this Special Issue break important new ground. Building on Pardo and Prato's foundational scholarship on the anthropology of legitimacy (Pardo ed. 2000, 2004; Pardo and Prato eds 2010, 2019), the articles are perhaps most distinctive in foregrounding the *temporal* dimensions to processes of legitimation — a topic that has been neglected in much of the literature. The contributions do so by focusing on controversies about legitimacy and health during an era of widespread turmoil and crisis. As anthropologists have long recognized, there is much to be learned by examining seemingly familiar and staid processes during periods of crisis, when the forces that render these processes ordinary cease to operate. For it is during these moments that the conditions of possibility of the normal and the everyday become visible. These essays provide us with the opportunity to seize upon crisis in order to *see* legitimacy in a new light — to do so by examining contexts in which it falters or fails.

As the contributors show, however, crisis is not all of one piece. Two different modalities of crisis are currently shaping struggles over legitimacy, community, health and the public. The first modality reflects the slow violence (Nixon 2011) unleashed on populations across the globe by processes of privatization and related efforts to redefine legitimate social life in neoliberal terms. Many of the articles foreground this problem. Collectively, they show the impact of privatization on an entire range of vulnerable groups, as well as the feelings of betrayal that ensue when governments prove unwilling to protect the vulnerable from assaults on their wellbeing. As the contributions show, new understandings of legitimacy, citizenship, health and the public are emerging all around the world as groups threatened by privatization draw upon the diverse cultural resources at their disposal to reconfigure communities of trust.

The contributions also shed important new light on the principles by which these emergent communities are configured. The Special Issue highlights two such principles. Some groups seek to protect themselves from privatization by seeking out ‘openings’. They reach across socio-cultural divides to incorporate new allies into a broader, more inclusive community of trust, a more inclusive public. Other groups, however, do the opposite. They commit themselves to ‘closure’ rather than openings and adopt practices that exclude rather than include. Like the January 6th mobsters, they reinforce rather than relax community boundaries, eschew difference, purge themselves of impurities, and establish a restrictive public.

The articles also draw our attention to a second modality of crisis, one that has had equally important effects on legitimacy, citizenship, health and the public. This second modality is one of sudden rupture rather than slow, steady assault. Rupture may be distinguished from assault in that it arrives without reason, out of nowhere. Furthermore, unlike assault, rupture threatens the entire population rather than a vulnerable segment of it. Indeed, rupture serves no one’s interests, and is difficult for everyone to comprehend (COVID-19, for example).[1] Unlike the slow violence of privatization, the sudden violence of rupture makes no effort to prescribe. It is not intent upon replacing an old form of order with a new one. Nor does it point in any new direction. It is directionless and pointless. Rupture undermines *all* forms of order. It is destructive rather than constructive.

One of the least remarked upon aspects of rupture is its impact on legitimacy. By its very nature, rupture tends to shatter existing understandings, expectations and relations. As a result, rupture involves the violent separation of what is from what was. Indeed, faced with rupture, people find that their accustomed ways of doing and believing no longer make any sense. Rupture thus leaves people without a meaningful history. It does so by destroying patterns of authority, delegitimizing the past, and leaving people stranded in a rootless present. But rupture does more than separate people from their past. It also denies them a future. Having lost any sense of where they have come from, people find it difficult to have any idea where they might be going. Indeed, they are caught in a condition of impasse (Caduff et al. n.d.), in which time seems to have come to a standstill.

Rupture thus renders nonsensical what had formerly passed as common sense. If people are to find a way out of impasse, they must develop a new common sense, a new framework of meaning, that can explain what has suddenly been rendered inexplicable. As the articles show, however, because past ways of doing and believing have been invalidated, generating such an account is difficult. Indeed, it involves an important element of ethnogenesis. It involves the

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[1] There are of course other examples of crisis. One thinks immediately of the economic crisis that descended upon the countries of southern Europe, with Greece being a particularly clear example (Panourgia 2011).

creation of new cultural worlds. In creating the world anew, people often have recourse to elements of belief that the old order dismissed as marginal or irrational. It is precisely because these notions were once ridiculed that they can now move to centre stage and can become the basis of a new common sense, a narrative that provides a new rationale for connecting the present to the past and the future.

By exploring how legitimation processes unfold in times of crisis, and by distinguishing between different modalities of crisis (slow assault versus sudden rupture), the contributions to this Special Issue shed important light on the forces that are generating new geographies of suspicion and trust across the globe. They do so by showing that each modality of crisis undermines existing patterns of legitimacy in distinctive ways, and confronts the populations thus affected with different dilemmas as they seek to resolve the crisis of legitimacy. They also identify the contrasting principles (openings, closures, ethnogenesis) that these groups employ as they seek to reconfigure legitimacy. But the Special Issue does more. In addition to helping us see the object of ethnographic enquiry in a new light, the contributions also have implications for the subjects who undertake such enquiries. They show how conditions of crisis compel us to re-think the conceptual categories that we employ to interpret ethnography.

Among the most important of these categories is ‘health’. The articles greatly enrich our understanding of this term by showing that, in the context of crisis, health has no clear or unambiguous referent. Indeed, groups across the globe associate health with a wide range of seemingly unrelated issues, from gang violence to intervention by spirit mediums, from road repair to waste disposal, from freedom of choice to the integrity of elections. In addition to documenting these wide variations in the meaning of health, the Special Issue does something more. It also draws our attention to a major shift in the landscape of legitimacy, a shift that is unfolding across the planet. Indeed, the articles document a growing suspicion of the rational-secular-bureaucratic as a way of engaging with the world, and the ever-more-widespread embrace of the non-rational, the spiritual and the emotive.

The conditions of crisis that are focus of the articles also help us see legitimacy in a new light. The contributions do so by analysing legitimacy in its absence — by exploring where people believe legitimacy *should* be located, who should be (but is not) exercising it on their behalf, and the sense of alarm and dismay that ensues when those expectations are not met. In the most diverse of circumstances, people believe that legitimate authority should be located in ‘the state’. By exploring contexts in which the state has lost legitimacy, by identifying the myriad locations where legitimacy is relocating, and by tracing the steps people take to re-establish legitimacy in these non-state locations, the contributions draw attention to the emergence of entire new topographies of order and conflict.

The articles further contribute to academic discussion and debate by suggesting the emergence of a distinctive form of legitimacy, one that is born of crisis. As suggested in the discussion of the January 6th Capitol Riot, populations facing conditions of rupture commonly often come together on the basis of ‘necessity’. What is distinctive about necessity is that it is seen as justifying virtually any kind of action, any challenge to what is, any effort at transformation. In other words, necessity is regarded as superseding all existing forms of legitimate order. The specific necessity that drives community formation varies according to context, as do the principles upon which the communities that seek to address it are configured. To take but two contemporary examples, in some settings communities coalesce around the necessity of protecting the nation — a concern that generates a community of suspicion, which is based on closure (that is, America's 'moral community' of mobster/patriots).[2] In other circumstances, however, communities come together around the necessity of saving the planet — a preoccupation that produces a community of sacrifice, which is based on openings (Nugent and Suhail 2021).

The articles also raise important questions about the meaning of the public, a term that is often associated with the citizenry. Because the contributions concern situations in which the public is being reconceived and citizenship is being redefined, they are very effective in bringing out the inherently political nature of these terms — which generally present themselves as apolitical. Karl Marx (1843) raised a related point almost two centuries ago in his reflections about the state. He argued that the state is an illusory sovereignty made up of imaginary citizens. In other words, the assertions of equality that underlie the idea of an undifferentiated citizenry conceal the enormous inequalities in wealth, power and possibility that characterize the real lives of the people that make up any political community. Neither the state nor the law addresses this problem. Indeed, as Marx argues, they conceal it. As Anatole France put it, 'The law, in all its majestic equality, forbids the rich and the poor alike from sleeping under bridges, begging in the streets and stealing bread' (1914: 94).

As the foregoing implies, the articles in the Special Issue also compel us to re-think the state. By focusing on contexts in which communities of suspicion, trust and sacrifice challenge the highly interested and arbitrary nature of government action, the articles illustrate Marx's point about the illusory nature of state sovereignty, and its inability to protect the rights of its citizens. But the contributions do something more. They also resonate with the writings of Max Weber. Weber (1946: 78) famously defined the state as 'a human community that (successfully) claims a monopoly on the legitimate use of physical force'. It is worth emphasizing that Weber did *not* define the state as an institution or a bureaucracy (Brown 1995), although he easily could have had he wished to. Instead, Weber was at pains to define the state as a human community.

This is a point that is unlikely to be without significance in that Weber wrote so extensively about the state and bureaucracy. It is also a point that is directly relevant to the contributions presented here. Indeed, the articles enrich Weber's emphasis on the state-as-community by asking the following question. In what circumstances do human communities come to see legitimate order as separate from the institutions that govern it? Put differently, in what circumstances do (some) citizens come to believe that they have been failed by the state? Furthermore, how might our understanding of the state change if we were to follow Weber's lead — if we approached the state as a human community that claims a monopoly on the right

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[2] Here, the articles echo the work of Agamben (2005), especially his analysis of Nazi Germany.

to use legitimate force (America's mobster/patriots, for example) rather than as an institution that exercises such a monopoly?

These considerations raise a second question that is related to the first. If, as Weber would have it, the state is reconceptualized as a human community rather than an institution, what are the forces that define the boundaries of such communities? Put differently, what are the forces that shape the parameters of the new communities of trust, suspicion and sacrifice that are emerging all around the world, in conditions of crisis? Which contexts promote tendencies toward closure — toward the formation of rigid, narrowly-defined communities of suspicion (whether in terms of race, class, gender, nation, and so on)? Alternatively, what circumstances encourage people to seek out openings — to explore the possibility of expanding communities of trust and sacrifice, so that they incorporate groups that were formerly regarded as suspect?

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The contributions to this Special Issue break important new ground in the study of legitimacy and health. They do so by exploring these issues during a time of great turmoil. By analysing seemingly familiar problems in a highly unfamiliar setting, the contributions reveal hitherto unexplored aspects of the processes by which particular forms of legitimacy come to be seen as legitimate. The articles do so in several ways. First, encourage us to re-examine the object of ethnographic enquiry; that is, they shed new light on the principles that underlie the formation of the emergent communities of suspicion, trust and sacrifice that are taking shape around the globe. Second, they have important implications for the subjects who undertake ethnographic enquiry. Indeed, they encourage us to look closely and critically at the conceptual categories that we employ in carrying out ethnographic analysis. It is difficult to imagine a more interesting or important set of essays.

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