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CHRONIC LIVING IN A COMMUNICABLE WORLD

Lenore Manderson and Ayo Wahlberg

Abstract:

By April 2020, COVID-19 lockdowns had restricted the movements of over half the world's population. As health authorities advise people living with chronic conditions to self-isolate because they are at particular risk of serious complications and death, we are once again reminded that the epidemiological split between communicable and noncommunicable disease is tenuous. In this article, we show how much more at stake for people living with (multiple) medical conditions than being “at risk” of infection of coronavirus during the pandemic. Isolation in homes is of course a challenge for everyone, but this is especially the case for those managing a chronic medical condition requiring lifelong, daily access to and use of medicines, technologies and medical advice. Moreover, as governments redirect resources and healthcare professionals to emergency respiratory care of COVID-19 patients, outpatient check-ups and so-called “elective” surgeries for those with conditions other than COVID-19 are being cancelled and postponed. The sheer scale of the unprecedented resources (in trillions of dollars) – already allocated to “flatten the curve” and thereby shield the intensive care capacity of national healthcare systems – raises the spectre of further austerity cuts which will impact on the care of people with chronic illness. We conclude by insisting that careful attention is paid to the long-term effects of the COVID-19 pandemic both on survivors of serious cases of COVID-19, who may have had their lungs damaged

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permanently and develop further sequelae, as yet understood. But we also draw attention to the importance of the continued care of people living with other lifelong medical conditions.

Keywords: Chronic disease, chronicity, COVID-19, illness work, prioritization

Media teaser: What is forgotten when the focus in health policy and practice is on a single disease?

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As COVID-19 continues to spread around the world we are, once again, reminded of the tenuous epidemiological split between communicable and noncommunicable conditions. The latter have long co-occurred with infectious disease, but the mix of the two has typically been illustrated in low and middle income settings seen to be struggling with a “double burden” of disease, as distinct from high income settings seen to have entered “the age of degenerative and man-made diseases” (Omran 1971: 738). Yet, as conditions like HIV, MRSA, influenza, and pneumonia have long shown, all regions and countries grapple with “double burdens,” particularly as both communicable and noncommunicable conditions have extended into long-term conditions. Moreover, it seems increasingly likely that COVID-19 will remain in circulation for some time globally, perhaps returning seasonally as one more health condition to be faced alongside so many others in countries around the world. The more relevant question pertains to how limited public health services, poor maintenance of infrastructure, uneven governance and lack of human, technical and fiscal resources at local and nation-wide levels shape *both* the spread of infectious disease *and* the (lack of) management of long-term, chronic disease throughout the world.

In this article, we outline three ways in which COVID-19 is already and will continue to impact on the lives of those already living with one or more medical conditions, likely for years to come. Firstly, those currently living with long-term medical conditions have been identified as particularly “at risk” of acquiring and succumbing to COVID-19. As a consequence, where there is not population-wide lockdown (as has been the case in countries such as South Africa and Serbia), people at risk especially have been told to self-isolate in their homes, cut off (to varying degrees) from their family networks and the medical services on which they rely. Secondly, as healthcare professionals and resources are redirected to tackle the emergency influx of intensive care patients requiring life-saving respiratory care,

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outpatient visits and so-called “elective” surgeries have been postponed or cancelled by persons living with medical conditions who are fearful of leaving their homes, by surgeons because beds are no longer available, and by hospital administrators for fear of infection. And finally, given the unprecedented amounts of resources that have been diverted or borrowed to manage the spread of COVID-19 and its social and economic costs in many countries, the spectre of endless austerity looms large. This makes it difficult for any country even to “just” maintain pre-COVID-19 levels of medical care for all patient groups. Given that COVID-19 is now a pandemic that has reached all corners of the world, we conclude by insisting that careful attention be paid to the long-term effects on the lives of those living with (multiple) medical conditions as well as to the survivors of serious cases of COVID who may have had multiple organs damaged permanently.

CONGENITAL, COMMUNICABLE, CHRONIC

In the midst of a global pandemic that has half of the world’s population in some kind of lockdown and breaking news covering rising infection and death rates by the hour, we are for a time distracted from the fact that, apart from COVID-19, every single day, molecular and cellular disturbances within individual bodies cascade into new medical conditions affecting millions of people throughout the world (Manderson and Warren 2016; Mendenhall 2012; Nichter 2016). Organs fail, immune systems weaken, metabolisms falter, cells degenerate and genes mutate. In many cases, untreated (or insufficiently treated) conditions lead to certain death, while in other cases, discomfort and debilitation intensify. For some, medical conditions are present from birth (e.g. congenital heart conditions) requiring immediate attention, while for others they “creep up” (Bury 1982; Charmaz 1993; Manderson and Smith-Morris 2010; Whyte 2012), perhaps in childhood (e.g. type 1 diabetes and increasingly type 2 diabetes),

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more often in adulthood (e.g. depression, dementia, arthritis and kidney disease). Others – as we are only all too aware of today – contract microbial infections that can pass with relatively little discomfort or result in temporary debilitations only, given access to appropriate medical care. Other infections and non-communicable diseases create a need for lifelong, life-saving medical treatment (e.g. HIV) or end in death. Even when cured, many conditions never quite disappear as sequelae linger on, as with cancer (Hansen and Tjørnhøj-Thomsen 2008) or the post-polio syndrome (Shing, et al. 2019); they contribute to greater severity on reinfection, with dengue for example, or they lead to related conditions (such as chicken pox and shingles, Sampathkumar 2016). What is more, mental and somatic health conditions often co-occur and interact, impacting on treatments and health-seeking efforts (Illangasekare, et al. 2013; Weaver 2016).

Huge numbers of people are affected by these various conditions, during acute phases and in their chronic aftermath. In 2016, 71% of all deaths globally - 40.5 million – were due to noncommunicable diseases, including cardiovascular diseases, cancers, diabetes and chronic lung diseases.¹ The burden of these diseases disproportionately affects lower income countries and populations (WHO 2018). In these same countries and communities, infectious diseases take their heaviest toll: in 2018 WHO estimated that nearly 98 million people were treated for schistosomiasis and continued to be at risk of infection; 228 million were estimated to have been infected with malaria, the vast majority surviving with compromised health status.² COVID-19 does not displace these diseases.

As a hundred years of medical anthropological studies have shown, far from being contained, such somatic disturbances inevitably spill over into social worlds and vice versa. Everyday activities of parenting, making food, eating, celebrating, socializing, bathing,

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exercising, working and more are shaped into new “kinds of living” (Wahlberg 2009) by the specificities and exigencies of the medical condition(s) at stake, treatment(s), and related requirements of care and support. Further, for immunological and biopathological reasons, these conditions often interact in ways that undermine the success of interventions. COVID-19 is not syndemic, but the virus is opportunistic, taking advantage of multiple co-infections and biological and social vulnerabilities in a world where syndemics disproportionately affect marginalised and less-resourced communities. Hence, the likelihood of severe disease and complications among older people infected by the coronavirus, when they already may have a number of non-communicable conditions, various infectious diseases, or when living with one of many auto-immune conditions.

At the same time, the extent of constraint that medical conditions can lead to is more often than not exacerbated by an appalling and stratified provision of and lack of access to medical services, care support and treatment, both within countries and globally. While political economies and ecologies of circulation sustained by human socialities, unsanitary exposures and non-human vectors (and all manner of intertwining between them) shape the spread of communicable conditions, noncommunicable somatic disturbances are often idiopathic (i.e. with no known biomedical cause), albeit increasingly tied to a host of “risk factors” and/or “social determinants” by epidemiologists and public health scholars. Health experts and advocates apportion blame in differing ways: some reproach individuals for their “unhealthy” behaviors while others admonish politically maintained social inequalities for disproportionately exposing those who are less well-off to pollution, poor sanitation, dire working conditions and industrially processed foods. As a number of authors have illustrated using syndemic theory as a frame (Hart and Horton 2017; Mendenhall 2012; Singer, et al. 2017), many infectious diseases, characterized as “neglected,” are both chronic in their course

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and coexist with non-communicable diseases, cardiometabolic disease particularly. The social conditions of vulnerability and risk are common to these two classes of disease; biologically, the relationships are more complicated, with likely confounding interactions between diseases, complications and treatments. Underpinning the prevalence of these conditions are unemployment and underemployment, food and housing insecurity. But, concurrently, acute infections have been assumed largely resolved, predominantly because of the effectiveness of early public health interventions – improvements in water and sanitation to address water-borne, food-borne and and water-wash infections, and vaccinations against specific viruses (polio, measles, diphtheria, etc.), even while distrust in the efficacy, safety and delivery of vaccinations have led to growing vaccine hesitance (Dube, et al. 2015; Kumar, et al. 2016; Larson, et al. 2014; Smith 2017). Concurrent with vaccination refusal, there has been considerable recalcitrance to health messages to reduce the use of antibiotics to head off antimicrobial resistance (Will 2020). Yet despite the disregard of government-mediated public health advice, there appears to be general confidence in medical interventions under epidemic conditions, hence the expectation that (and pressure on) scientists to develop candidate vaccines against COVID-19.

In these ways, infections and non-communicable diseases co-exist, and complicate the other, inhibiting treatment strategies, for example. They do not cancel each other; rather conditions develop independently and so coexist, and there are few instances where some level of immunity is conferred because of prior history. Moreover, preexisting medical conditions are seen to compromise immune responses to new infections as implicated in definitions of vulnerability to new infection and to its seriousness (critical infection and risk of death). Not only has COVID-19 spread to almost every country in the space of three months, it is also spreading at a time when more people than ever, everywhere, have been diagnosed and are

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living with diabetes, tuberculosis, cancer, HIV, malaria, asthma, kidney disease, lupus, heart conditions, dementia, rheumatoid arthritis, depression and many more medical conditions. It is therefore imperative that close attention is paid to the ways in which ongoing efforts to contain a pandemic are impacting on the lives of those living with medical conditions other than COVID-19.

ISOLATED AT RISK

In a world with multiple diseases, millions of people lead (or seek to lead) insulin-lives, chemo-lives, immunosuppressant-lives, dialysis-lives, factor-lives, antiretroviral-lives, antidepressant-lives, memantine-lives transplant-lives, corticosteroid-lives, and more (Constantinou 2012; Dokumaci 2020; Greco 2019; Kingod 2020; Lee 2019; Livingston 2012; Whyte 2015). At the same time, many interlace biomedical treatments with so-called “traditional, complementary and alternative” treatments. Others either have no available options other than these latter forms of therapy or they actively favor them over biomedicine (Hardin 2016; 2018). Such therapeutic pluralism notwithstanding, there is nothing inherently chronic about conditions like type 1 diabetes, cancer, HIV, congenital heart defects or kidney disease; rather these medical conditions are *made* chronic given access to life-saving and prolonging treatment as well as adequate care and support (Kierans 2020). Moreover, as people grow older, the cascading of multiple medical conditions can complicate treatment and its coordination, with possible compromises as treatment costs accrue (Manderson and Warren 2016).

Given the techno-medical underpinnings of many forms of chronicity, sustained access to appropriate health care is crucial. In some countries, chronic care infrastructures (Langstrup 2013) are in place, providing people with the outpatient care and treatment to allow them to

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live as well as possible (albeit always in stratified ways). Even in countries where health care is uneven and unequal, as in South Africa, programs for integrated chronic disease management have been developed to address the co-occurrence of HIV and various non-communicable diseases. For millions, however, such infrastructures are at best patchy, leading to lengthy struggles for access to treatment, which sometimes succeed and often times fail, ending in suffering and untimely death (Moran-Thomas 2019). Chronic living is a daily reality for an ever-growing number of people and their families and loved ones. Yet, how chronic living takes form is dependent not only on failing biologies (those cascading molecular and cellular disturbances), but perhaps more importantly, on the political economies and ecologies that determine families' life conditions, their care networks and their access to healthcare. Likewise, the socio-cultural incorporations and/or stigmatizations of medical conditions within communities are foundational to how chronic living is shaped in different parts of the world.

Homes are most often the locus of the often creative and experimental ways in which people go about daily lives swayed by medical conditions, whether as persons living with medical conditions or as their caregivers and loved ones who may likewise also be living with medical conditions. This is what chronic living is – the manifold ways in which people attend to, experience and take care of themselves and their medical conditions often with the indispensable help of loved ones, in differing life conditions and with stratified access to (life-saving) medical treatment and care. Even so, it is not always possible to distinguish among householders as caregivers or not, as different individuals move in and out of care provision depending on time, availability, need and action of care. Caregivers may themselves be living with chronic conditions of various levels of severity, and may intermittently experience poor health or decreased capacity to provide care due to infection (of which upper respiratory

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infection is most common) or injury. As numerous anthropological studies have shown, everywhere, households vary in size, relationship of household members, age, capacity to self-care, and the capacity and willingness to care for others (Manderson, et al. 2016a; Manderson, et al. 2016b; Mkhwanazi and Manderson 2020; Nxumalo, et al. 2016).

Given these insights from decades of anthropological research, it is conspicuous that discussions of the management of pandemics – not only COVID-19 but also Zika, Ebola and H1N1 before it – take little account of pre-existing conditions other than as an indicator of vulnerability of serious infection and death. Householders are asked – in some cases forced – to stay at home, and while COVID-19 remains virulent, self-isolation may continue for some months. This needs to occur concurrently with self-care for pre-existing chronic conditions, on the assumption that this will not be problematic: that notwithstanding isolation, people will be able to present to clinics for care such as dialysis; that people will be able to monitor conditions and act in the case of fluctuation (of glycemic index for instance); and that people will be able to access doctors and pharmacists for new or repeat prescriptions and for the treatment of other emerging pathologies.

Chronic living very often requires what Corbin and Strauss (1985) termed “illness work” and Mattingly and colleagues (2011) subsequently termed “chronic homework” on the part of those living with medical conditions and their family members. As Corbin and Strauss point out “when the ill are sent home from the hospital after acute phases, they are often accompanied by much technology--procedures, drugs, machinery--and some direction in how to utilize this technology. But management of an illness in the home is not accomplished without difficulty and a great deal of effort, unless the regimens are relatively simple and do not greatly interfere with the normal flow of life” (1985: 224-5). People living with HIV must stock antiretroviral medicines to be taken daily in combination. The task may be relatively

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straightforward where there is universal healthcare and access to pharmacies, but in rural parts of Africa, India, China and elsewhere in the global south, acquiring and maintaining stocks of medicine often involve long travel journeys and prohibitive out-of-pocket expenses. Patients diagnosed with chronic kidney disease may require 3-hour dialysis sessions four times a week, and while some are able to equip their houses with home dialysis units, others must make their way to hospital-based dialysis centers many times per week, if they are able to access medical care at all. Those living with and self-managing mental health conditions must calibrate medication intake with changes to their working and living routines (if possible) and attending psychotherapy sessions (if available). And Type 1 diabetes patients learn to measure and monitor their blood glucose levels in order to calibrate their intake of insulin using complex day-to-day calculations of symptoms, timing of meals and physical activity. Each chronic condition has its specific forms of homework which can be more or less onerous; each requires consistent access to particular medications and technologies. At the same time, regular interactions with healthcare professionals to monitor any changes or deteriorations in health are crucial. In these ways chronic health conditions need ongoing care and screening can be critical to assess changes. During COVID-19 lockdowns, both caregivers and those with serious non-communicable diseases must adjudicate conflicting messages and perform their own triage: to remain in isolation and allow time to determine outcome (hoping either that certain symptoms will subside and prove unimportant, or that restrictions on everyday social interactions will be lifted); or seek help as symptoms may become crises demanding action despite risk. Ironically, they are ‘at risk’ of their known conditions while in self-isolation to protect themselves from the virus they are ‘at risk’ of dying from.

Yet the everyday medical needs and routine health care of people with acquired and cumulative health problems has received little attention in the context of information on

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COVID-19 and its implications for householders and families. The primary message is that any chronic condition increases the severity of coronavirus infection, and its likely outcome (hospitalization and/or death). But beyond this, how to act in managing a chronic condition, or multiple conditions, as is common with increasing age, is uncertain in pandemic lockdown. And while this is challenging in high income settings, these challenges are intensified by inequalities and accrue in low and middle-income centers where living with multiple chronic conditions is tightly correlated with precarity, and access to and the affordability of care is always calibrated against other demands, directly and indirectly, on time and income. In addition, there is still little clarity and concern about what kinds of care might be provided to people with chronic conditions under conditions of constraint, and the risk of being infected by coronavirus influences care-seeking.

REPRIORITIZING HOSPITALS AND PRIMARY CARE CLINICS

When the Prime Minister of Denmark Mette Frederiksen announced that the country was going into lockdown on 11 March 2020, the National Board of Health was instructed to prepare an emergency plan for how the healthcare system would be able to cope with an expected influx of COVID-19 patients requiring intensive care which epidemiologists predicted would peak somewhere around the end of April 2020. Two days later, the Board sent out a “Memo on reduction of hospital activity in connection with COVID-19” (Sundhedstyrelsen Sagsnr. 04-0101-35) to hospitals throughout the country. Among other directions, hospitals were instructed to free up staff to look after hospitalized COVID-19 patients: “The Board of Health deems that this can be achieved by reducing outpatient activities in a number of clinical specialities [since] all forms of outpatient check-ups for patients with a stable illness can be postponed or redirected.” Likewise, diagnostic and

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treatment “guarantees,” which had been enshrined in law in 2002 to ensure that serious diseases were detected earlier and treatments commenced, were suspended so that resources could be rerouted to the expected surge in intensive care treatments. In Australia, strict social distancing and isolation took effect from 1 April, and hospitals and surgeons were given one week notice to suspend all non-urgent elective surgery. While private hospitals lobbied against this on the basis that they were economically dependent on such procedures, there was a rush on arthroscopies, bariatric surgery, gastroscopies, tonsillectomies and wisdom tooth extractions. Concurrently, hospitals increased intensive care facilities with ventilators to accommodate increasing numbers of patients with COVID-19; physiotherapists began to be retrained in critical care procedures; and general practitioners were assigned to special COVID-19 response teams.

In resource poor settings everywhere, there is limited capacity to provide care and save lives if infection rates escalate. Many public hospitals are in poor condition, and even basic hygiene may be lacking: working taps and sanitation are compromised; basins for handwashing lack soap (Guo, et al. 2017; Street 2014) and e.coli, staphylococcus and other bacteria, frequently present on theatre staff hands (Matuka, et al. 2018), contribute to nosocomial infection (Han, et al. 2019; Saleem, et al. 2019; Singh-Moodley, et al. 2018). In South Africa, beds are too close in ICU wards in both public and private hospitals to ensure isolation (Mahomed, et al. 2017). Hence South Africa’s harsh 21-day lockdown in an effort to avert disaster. In India, following Prime Minister Narendra Modi’s call for a nationwide lockdown on 24 March, outpatient departments were closed and some hospitals were turning away patients with chronic conditions (Krishnan & Bengali 2020). And in the United States, at time of writing already with the same number of cases of Italy, Spain and France combined, there are field hospitals in New York, Seattle, Worcester, MA, Los Angeles and Philadelphia,

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at least, with tents, convention centers, sports arenas and parking lots all repurposed to meet the need for acute emergency care. The photographs of these sites are visual ghostly echoes of the Spanish flu (1918-1920) and the polio epidemics from the 1930s to 1960s.

Given these developments, the knock-on consequences for people living with (multiple) long-term medical conditions are potentially life-threatening and at a minimum problematic. All have a lifelong need for access to medical care and advice as they go about their chronic homework on a daily basis. In high-income countries, such care has been routinized into regular outpatient check-ups where medical tests are taken and results used to calibrate treatments, leading to lives that are routinely punctuated by interactions with health professionals. The frequency of such check-ups depends on the severity of conditions as well as possible complications and escalations, and these can happen at any time. In low and middle income countries, integrated chronic care may be provided at a primary health care level or at hospitals, with patients responsible for paying visits to outpatient departments as needs arise, often paying out of pocket. Their health may already be compromised as they manipulate self-care tasks to balance the difficulties of adherence and the need to appear compliant with advice (Naemiratch and Manderson 2006). For millions of people, not least in India and China, regular care for chronic conditions is hindered by lack of funds or means to travel to hospitals and lack of cash to pay for consumables including needles, gloves, dressings, and medication. In addition, the outreach work of community health workers and others providing direct support to people with chronic conditions, such as provided to people with TB and HIV, for instance, is compromised, and there is no clear way to safely balance risk of infection and quality care in community settings (WHO 2005b). A growing number of older people with chronic conditions including cardiometabolic disease and cognitive decline rely on familial and community level support. We know that frail older people in areas severely impacted by

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HIV and AIDS have limited care, and that this is further complicated by gender, family composition and ethnicity (Madhavan and Brooks 2016; Mee, et al. 2016; Schatz, et al. 2018; Whyte 2015). This group is particularly vulnerable biologically to the virus, but also socially due to lack of adequate basic care, truncated social networks, and limits to family and community capacity to extend care as needed (Harling, et al. 2020).

Further, people with chronic conditions may already prioritise the health of their children over their own, and the risk of infection in the community reduces the likelihood that people whose health is already compromised will present for medical advice. With loss of work and fewer opportunities for income generation, more people than ever will only be able to pay for medical treatment sporadically, leading to suboptimal care and untimely death (Kierans 2020; Moran-Thomas 2019). The reprioritizations of health care that COVID-19 has brought in its wake are disrupting the provision of medical care in ways which will almost certainly leave their mark on national mortality rates in 2020.

PANDEMIC AUSTERITY AND INEQUALITY

From the late 1990s, the World Health Organization (WHO) issued warnings of the potential of pandemic viral disease, and that preparedness planning was critical. Within WHO, guidelines were developed in the context of the 2003 SARS epidemic; the Checklist for Influenza Pandemic Preparedness Planning provides the strategies and lexicon – of social distancing, for instance – that we use today (WHO 2005b). These were revised in 2009, 2011 and 2013 with further outbreaks of SARS, avian flu (H5N1) and H1N1. As illustrated elsewhere, most countries in Africa responded by developing plans to reduce transmission, particularly across rather than within national borders (Sambala and Manderson 2017). Even so, the WHO guidelines anticipated well the broad areas that have been canvassed and subject

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to state control during COVID-19. These include the control of trade and population movement, surveillance and case investigation, clinical management and measures to control community transmission, including those that define the current pandemic -- personal hygiene measures, “social distancing,” and the maintenance of essential services (WHO 2005b). While the lethality and local inflections of the Ebola epidemic highlighted the limitations of these guidelines, the scope of the COVID-19 pandemic was unimaginable (see also Caduff 2015; Lakoff 2017).

It is safe to say, even at time of writing, some four months into the calendar year, that never before have so many resources been directed to manage the spread and impact of a single medical condition in such a short period of time. Further to the emergency resources being spent on bolstering intensive respiratory care capacity in hospitals, economic and social activities in entire countries, affecting over half the world’s population, have been drastically shut down. Rises in these countries’ unemployment rates are literally off the charts, leaving millions of families, already employed day-to-day in precarious and vulnerable working and living conditions, in devastating circumstances. Given that those who are less well-off are disproportionately affected in their health, many of these families have members already living with managed (to varying degrees) medical conditions. In countries like China and India, for example, migrant laborers have been severely affected, trapped overnight by mobility restrictions and losses in income, and, as Onoma (this issue) describes for Ebola, they are vulnerable to xenophobia. Government rescue packages in USA, Europe, Japan and Australia are being put together in the trillions of dollars, but even these consider citizenship a prerequisite for state support. Immigrant workers and others whose civil status is ambiguous and residence tenuous, and those who are structurally vulnerable (Quesada, et al. 2011) and

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subject to structural violence (Farmer 2006), whose health is already compromised, are most likely at risk of exposure to the pathogen and least able to gain access to timely health care. Further, responding to COVID-19 requires that funds and other resources are diverted from other areas of care, placing heavy demands on health systems even with good governance, quality care and reliable supply chains.

The COVID-19 pandemic has come at a particularly delicate time for healthcare systems the world over. According to the OECD, the number of hospital beds per capita “has decreased over the past decade in most OECD countries, falling on average from 5.6 per 1 000 population in 2000 to 4.7 in 2015” (OECD 2017). While part of this drop can be explained by a move towards day surgery and reductions in hospitalization rates, “in many European countries, the financial and economic crisis, which started in 2008, provided an additional stimulus to reduce hospital capacity in line with policies to reduce public spending on health” (OECD 2017: 172). All the while, chronic care infrastructures based on routinized outpatient check-ups have been scaled up while under increasing pressure from austerity policies in the past decade (Hiam, et al. 2020). China’s healthcare system is in crisis following decades of commercialization in the health care sector, shortages of health care professionals and a severely lacking primary healthcare system (Song 2017). And in resource poor settings like Botswana, Malawi, Burkina Faso and Papua New Guinea, anthropologists have shown how fragile health care systems generate perpetual triage (Nguyen 2010) forcing healthcare professionals to make “tragic choices” (Calabresi and Bobbitt 1978) on an almost daily basis, just as doctors in Milan, Madrid and New York have been forced to do in 2020 as severe COVID-19 cases overwhelmed healthcare systems. In resource-poor settings, patients seek to make their illnesses visible as their families seek healthcare in local hospitals with inadequate means, chronic shortages of medical supplies and defective diagnostic technologies leading

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doctors and nurses to improvise and make do (Livingston 2012; Street 2014; Wendland 2010). These healthcare systems and the healthcare professionals who work in them make chronic living possible, for as already noted, without access to dialysis, antiretroviral treatment, insulin or chemotherapy, people living with diabetes, chronic kidney disease or HIV die.

Whatever gains may have been made over the past decades to support those living with (multiple) medical conditions, 2020 may well mark a turning point for the worse. The pressures that healthcare professionals worldwide were already facing prior to COVID-19 are likely to intensify given the kinds of resources that are currently being redirected and rerouted. Indeed, it is not unlikely that the COVID-19 pandemic will be followed by an austerity pandemic as governments take stock of and pay for the extensive costs of “flattening the curve” and emergency intensive care. The likelihood of resilience within health services and among individuals is far greater in wealthy countries where there is a stronger resource baseline (household income, numbers of health care professionals, skills and technologies) compared to poorer countries – as HIV showed when AIDS gouged out some of its most qualified professionals. Healthcare systems are already overstretched, and healthcare workers are exhausted with many having lost their lives at the frontline of COVID-19. A massive effort will be required to “normalize” healthcare once the current emergency has settled, at least for a time. Further resources are sure to be directed towards preparing for the next pandemic, all of which will unavoidably divert resources from other priorities, not least once austerity kicks in.

CONCLUDING REMARKS

Until 2020, global health agendas had been mobilizing around what the WHO and others have called the “global chronic disease pandemic” (Wahlberg and Rose 2015; WHO 2005a). In

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some ways a “success” story as medical advances have allowed both communicable and noncommunicable conditions to become long term, given access to treatment. Unless concerted efforts are made, 2020 will not only be remembered for the deaths caused by COVID-19, the overstretched healthcare systems and the mass unemployment caused by national lockdowns, but also for the collateral consequences for persons living with (multiple) long-term medical conditions. They are and will continue to experience deteriorating life conditions. There is nothing new about prioritizing within health care systems; this is a daily reality for all hospital administrators with limited resources, especially those in less resourced parts of the world. There are limits to how much healthcare workers can do and it is clear that as they are asked to divert their time and energies to tackle COVID-19, the care of people with other medical conditions will suffer as a result. At this point, we do not know how long states of emergency will remain in place. What we do know is that chronic living just became that much more difficult and perilous. Indeed, we may well be able to discern COVID-19 in the mortality rates for numerous chronic medical conditions in 2020 and beyond.

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NOTES

¹ https://www.who.int/gho/ncd/mortality_morbidity/en/;

<https://www.who.int/data/gho/publications/world-health-statistics>

² <https://www.who.int/news-room/fact-sheets/detail/schistosomiasis>;

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