
Long Covid/Long View: Searching for Legitimate Care

Judy Arnold

(Pellissippi State Community College, Tennessee, USA)

drj10sc@aol.com

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 Knoxville 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.

References

- CDC. 2021. Post-Covid Conditions. 16 September. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>
- Channa, S. M. 2022. Negotiating Power over Human Bodies: Populism, People and the Politics of Health in Delhi. In I. Pardo and G.B. Prato (eds), *Healthcare and Public Health: Questions of Legitimacy*. Special issue, *Urbanities-Journal of Urban Ethnography*, 12 (Suppl. 6): 72-77.
- Gallup. 2021. Critical Care: America vs the World. 21 April. <https://news.gallup.com/poll/248081/westhealth-gallup-us-healthcare-cost-crisis.aspx>; accessed 5/10/21.
- Kayaalp Jurich, E. 2022. Covid-19 Pandemic, Health Policy and The Question of Legitimacy in Turkey. In I. Pardo and G.B. Prato (eds), *Healthcare and Public Health: Questions of Legitimacy*. Special issue, *Urbanities-Journal of Urban Ethnography*, 12 (Suppl. 6): 66-71.
- Morens, D. M., Taubenberger, J. K. and Fauci, A. F. A. 2021. Centenary Tale of Two Pandemics: The 1918 Influenza Pandemic and COVID-19, Part I. *American Journal of Public Health* 111: 1086-1094, <https://doi.org/10.2105/AJPH.2021.306310>
- Pardo, I. and Prato, G. B. 2019. Ethnographies of Legitimacy: Methodological and Theoretical Insights. In I. Pardo and G. B. Prato (eds), *Legitimacy: Ethnographic and Theoretical Insights*. New York: Palgrave-Macmillan.
- Pardo, I and Prato, G. B. eds. 2019. *Legitimacy: Ethnographic and Theoretical Insights*. New York: Palgrave-Macmillan
- Spinney, L. 2020. What Long Flu Sufferers of the 1918-1919 Pandemic Can Tell Us About Long COVID Today. *Time News Ideas*. 31 December, <https://time.com/5915616/long-flu-1918-pandemic>
- Tunstall, L. 2015. Backgrounder, Making Sense of the American Healthcare System: A Primer. 22 October, <https://evidencenetwork.ca/backgrounder-making-sense-of-the-u-s-health-care-system-a-primer-2/>
- Weill, J. A. Stigler, M., Deschenes, O. and Springborn, M. R. 2020. Proceedings of the National Academy of Sciences. Aug, 117 (33):19658-19660, DOI:10.1073/pnas.2009412117