

The Covid-19 Crisis and the Experience of Polio Survivors: Life Before and After a Pandemic

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My name is Izumi Otani. This time it's online, but I'm very happy to see some of the people I met in Wuhan in October of last year again. This photo was taken in the park across from the Wuhan meeting venue. I remember talking to local citizens in the park about my wheelchair. Since then I've been praying that these people are OK.

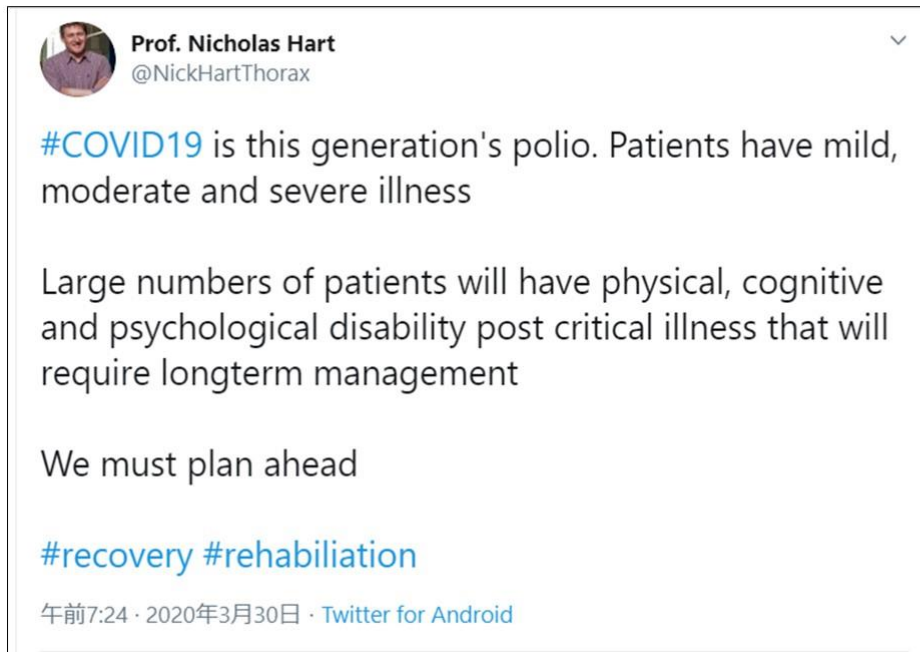


In Wuhan,
2019.10.13

Today efforts are being made to develop a vaccine that will resolve the COVID-19 pandemic, and polio is seen as an example of a case in which this has been successfully accomplished. On June 19th the WHO has declared Nigeria free of wild polio and reported that it only remains in two countries, Afghanistan and Pakistan.

So will COVID-19 be “resolved” by the development of a vaccine? Assuming it *is* “resolved,” what kind of resolution will this be? One of UK Prime Minister Boris

Johnson's doctors tweeted, "COVID-19 is this generation's polio. ... We must plan ahead." The future of COVID-19 remains unclear. Let us consider this situation based on our experience of polio.



Prof. Hart was one of the doctors that treated UK Prime Minister Boris Johnson.

From the start of the 20th century to the 1950s, outbreaks of polio were seen all over the United States, Canada, the United Kingdom, and Japan. Looking at the records from 1960 when I contracted the disease, in Japan the worst outbreak was in Hokkaido. The mortality rate was 17%, and "iron lungs," the only treatment method at the time, were gathered from all over the country. The barriers to vaccines developed overseas being approved in Japan, the political barriers with the Soviet Union during the cold war, and the blatant discrimination against and exclusion of the families of patients overlap with what is happening today. When I was ill, I was isolated in a hospital for two months together with my mother. I was eight or nine months old so of course I have no memories of that time, but looking back I can imagine the suffering of my mother and my family. In Hokkaido there are records of the houses of infected people being labeled with a special mark.

Polio is normally contracted in early infancy, and after surviving high fever and respiratory paralysis one in a thousand patients suffer aftereffects of varying degrees of severity, mainly involving paralysis of the limbs. Among adults this rate is one in seventy-five. For polio survivors, this disease is by no means in the "past."

Polio is not a disease of the past

- Various aftereffects, both mild and severe, remain
- There are new patients and secondary infections caused by live vaccines
- Globalization is expanding the risk
- Post Polio Syndrome leads to secondary disabilities
- The number of doctors and other healthcare professionals who can treat polio and PPS has drastically decreased

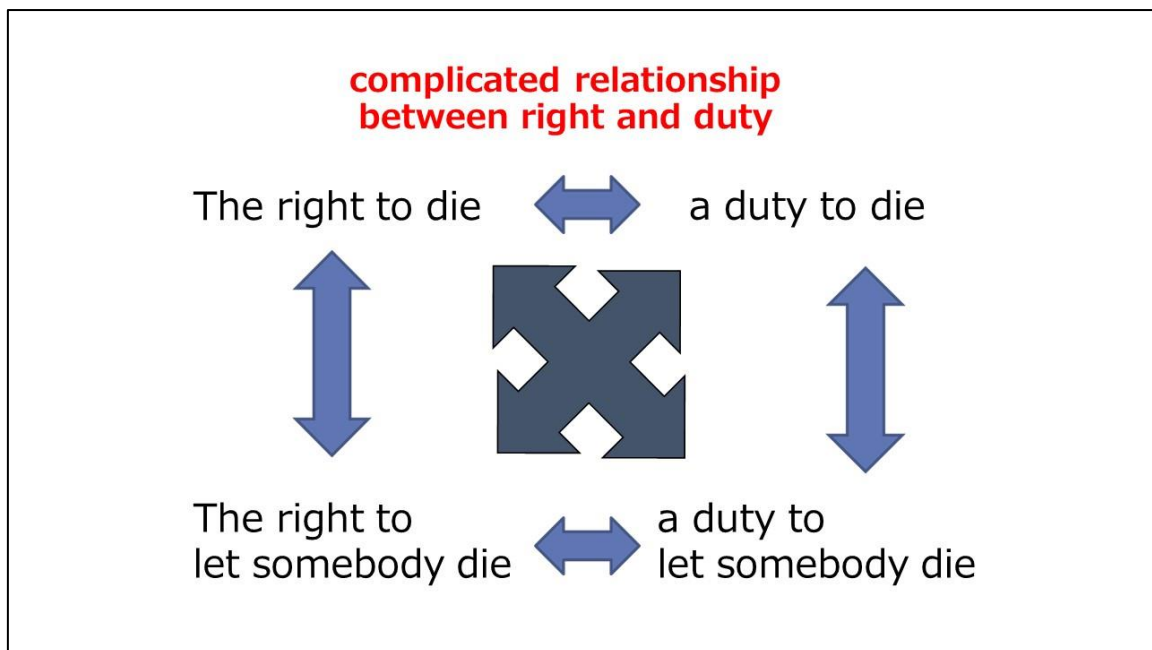
In Japan the number of people contracting polio has drastically declined since a cheap live vaccine became mandatory in 1961. Nevertheless, a very small number of cases of polio symptoms caused by the live vaccine and secondary infection continued to arise. Ironically, after decades in which the number of patients has steeply declined, for doctors active today polio has become a disease of the past. Nowadays there are few hospitals ready to take over from the veteran doctors and paramedical staff who are treating polio survivors and people with “Post-polio syndrome (PPS).” The biggest problem is that with the number of doctors capable of diagnosing polio rapidly declining, when harmful effects of vaccination do arise, not only is early detection and treatment delayed, but patients who are not diagnosed slip through the cracks in the welfare system.

Concern about this situation sparked a movement to switch to an inactivated vaccine, and this transition was finally made in 2012, but the new vaccine requires several injections. In the meantime, because legal enforcement has weakened and public assistance has been limited, amidst the progress of globalization the risk of infection continues. With vaccinations having been halted during the COVID-19 crisis, the reopening of the movement of people prioritizing the economy will increase this risk. The most immediate concern is the tremendous danger posed by the Olympics and Paralympics. This is the second reason that polio is not a disease of the “past.”

In the post-war era the welfare system had not yet been put in place, and most Japanese polio survivors got by through a combination of small schemes and self-help. Female patients faced the additional hardship of gender discrimination.

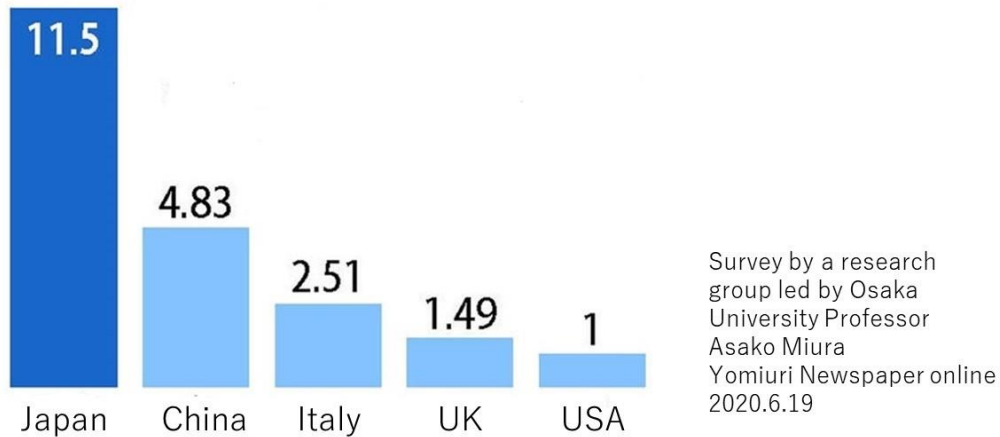
By the way, polio survivors don't know what it's like to be "normal," so we believe without question that the enormous efforts we are always making are "normal." For example, where a normal person might say they "can't" do something if it requires a lot of effort, polio survivors will often say we "can" do something even if it is an enormous struggle. This tendency is called the "polio temperament." When we get past middle age, most polio survivors develop PPS – post polio syndrome; they become paralyzed in new places, and other symptoms such as pain and fatigue become markedly more severe. This is the third sense in which polio is not a disease of the past.

Now, with many polio survivors entering old age, we find ourselves in the midst of this COVID-19 pandemic. So what is happening today in the wealthy countries that, like Japan, were quick to "eradicate" polio? In Europe the treatment of elderly infected people is openly abandoned, and in nursing homes for the elderly not only the mortality rate but the unconfirmed excessive mortality rate are higher than among other groups.



Last October in Wuhan I presented a report entitled "Discourse on Euthanasia/Death with Dignity: 'Right to Die' and 'Duty to Die' in an Aging Society." I discussed a complicated situation in which the movement that is supposed to be for the right to die ends up creating a duty to die, and a duty of families and doctors to have elderly people and people with disabilities die. Today in Europe and America this is becoming a reality under the name of "triage."

Percentage who think “people infected with COVID-19 are suffering the consequences of their own actions”



Slightly different signs can be seen in Japan, where there are not as many infected people and deaths as in America and Europe. At the end of June, it was reported that according to a survey 11% of Japanese feel that “people infected with COVID-19 are suffering the consequences of their own actions,” ten times the figure in the US and the UK. This should be considered in conjunction with and the circumstances in which, even though unlike in most other countries there has been only a “request for self-restraint” without legal enforcement, the names of entertainment businesses that have stayed open have been published by the government and on social media, damaging their reputations.

It is often said that the virus is frightening because you can't see it. What is truly frightening, however, are the changes in people and society incited by the fear of what cannot be seen. A neighbor you had trusted can easily become a threat. Discrimination or an attitude of superiority that had been hidden under jokes or kind words is laid bare. People are becoming angry and lashing out in their daily lives, and voices saying, “You're not the only one who has it tough” are growing louder. In the midst of a wartime-like “state of exception,” elderly people and people with disabilities coming forward and asking that the care of others be given priority in a triage approach is being praised as virtuous. It must be made clear, however, that this idea of “virtue” is unmistakably tied to essential workers who preserve the lives of elderly people and people with disabilities being treated as disposable.



FDR was the only American President who had a severe physical disability

This statue was erected at the request of people with disabilities

With the FDR statue in Franklin Delano Roosevelt Memorial Park (Washington DC)
2016.6.26

I've prepared one more photograph, so please take a look.

This is a photo of me and the statue of FDR in the Franklin Delano Roosevelt Memorial park in the suburbs of Washington D.C.. President Roosevelt was a polio survivor who used a wheelchair. FDR was the only American President who had a severe physical disability while in office, but in the pre-war era in which the main medium was radio, Americans had no idea that FDR used a wheelchair, and this fact was rarely reported in the media. FDR hated being seen in a wheelchair more than anything. This is a reflection of the view of people with disabilities at that time.

A hundred years have now passed since FDR contracted polio. This FDR statue was erected at the request of an association for people with disabilities. It reminds us that in America there was a movement of people with disabilities along with the feminist and african-american civil rights movements. With the #MeToo and BLM movements spreading beyond the barriers of sex and race, we can see signs of a bridge and solidarity between people with a high rate of infection and mortality who perform essential work under poor circumstances.

With the advance of technology, the potential to transcend barriers to movement and information has grown broader. This online seminar is one example of this trend. At the same time, however, we must not forget the value that comes with sharing the same space. As post-polio survivor who has lived from the pre-COVID-19 period to the post-

COVID-19, I sincerely hope to be able to welcome you here in Kyoto someday soon.

Thank you for listening.