Declassified[1]
AS/Soc (2021) PV 08add
28 September 2021
Asocpv08add_2021

Committee on Social Affairs, Health and Sustainable Development

Minutes

Public hearing on "Long Covid", held in a hybrid manner, on Thursday, 9 September 2021

As a follow-up to Resolution 2373 (2021) on "Discrimination against persons dealing with chronic and long-term illnesses", the Committee **held** a public hearing with the participation of:

- ✓ **Ms Martine Wonner**, member of the Committee & former rapporteur, (France, ALDE)
- ✓ **Ms Laurence Trastour-Isnart**, member of the Committee (France, EPP/CD)
- ✓ **Mr Risto O. Roine,** Professor of Neurology, Turku University Hospital & Chair of the Board, Finnish Brain Council
- ✓ **Mr Daniel Altmann**, Professor of Immunology, Imperial College London

Mr Luís Leite Ramos, Committee Chairperson, introduced the invited experts and opened the hearing.

Ms Trastour-Isnart expressed her satisfaction with the holding of this timely hearing. People affected by Long Covid were genuinely suffering. She herself had had it for more than a year and it was very difficult to deal with. After more than a year of the pandemic many countries still did not accept this reality. The Council of Europe member States should accept their responsibility. In January, the Assembly had adopted a resolution on discrimination against people suffering from chronic and long-term diseases which had been instigated by Martine Wonner. This had been an important achievement. It was time to establish a harmonised treatment protocol for Long Covid patients. By now, the world had been able to assess the consequences of the Covid-19 crisis. Humanity had paid a heavy toll. Many Covid victims had suffered from discrimination. They had not been sufficiently listened to, supported, and treated during the Covid-19 crisis.

Long Covid involved many symptoms which continued for a long period of time, such as muscular weakness, fatigue, itching, acute pain, heart problems, high blood pressure, cardiac palpitation, cognitive problems in terms of attention and memory, sleep disorders, neurological disorders, migraines, and the loss of taste and/or smell, eye or throat problems, and pulmonary disorders. All these symptoms could be long-term side effects that prevent the resumption of normal life. While the number of individuals suffering from Long Covid was difficult to ascertain, it would appear to be between 10 and 20% of patients, or approximately seven million people in the Council of Europe member States. Due to lack of understanding of this condition, many people had been accused of not being willing to work, while they were suffering from acute physical and psychological problems.

There existed many testimonies from people suffering from Long Covid. For example, Pauline had been disregarded for almost a year during the pandemic and suffered in silence from side effects without being taken care of; Celine had had Covid for 11 months and could not walk or even stand up any longer, while the social security services had officially refused to view this as an occupational disease, because she had not been put on oxygen; Annabelle George had written a book about suffering from Covid from March to September 2020. The response to this situation had to be comprehensive. Every member State should report on the support provided to the people suffering from Long Covid. It should become part of a disease nomenclature. Doctors should be informed so that they provided relevant care for their patients. An efficient system for two types of cases was needed: for people, who had tested positively for Covid-19, and for people who had not been tested and were therefore unable to prove that their health problems were due to Covid-19. A minimum guarantee and medical care for these patients had to be ensured, including financial coverage of the treatment, drugs, and therapeutic care, as well as psychological assistance and rehabilitation. All these measures should be financially guaranteed by the state. Society should take care of its most fragile and weak members, and this was not always the case in present times. The Assembly should tackle this issue and there should be a collective response. It was crucial to exchange experiences and to co-operate.

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[1] The minutes were approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 28 September 2021, held in a hybrid manner.

Ms Wonner noted that Long Covid was not sufficiently known or recognised, and increasingly more people were suffering from it including young adults and people who had no pre-existing medical issues or had not been hospitalised. In France, more than 20% of such patients were still presenting symptoms of Covid 5 weeks after contracting the disease, and 10% after three months. In February 2021, according to WHO, around 1 out of 10 Covid-19 patients were still suffering 12 weeks after falling ill, and many for much longer periods of time.

Chronic and long-term illness hampered the full enjoyment of human rights and fundamental freedoms. The situation of people affected by Long Covid was even more difficult, as it did not receive the attention it deserved. In 2021, WHO had organised seminars to expand knowledge on post-Covid conditions, listening not only to scientists and doctors, but also to patients. Unfortunately, WHO representatives had not been able to attend today’s hearing, but they had expressed their support and availability for providing advice on these issues in future. It was essential for individuals with disabilities resulting from Long Covid to be aware of their rights. They should know how to secure available services and support. They should talk to health practitioners. It was also essential for such services to be accessible and efficient. For this, legislative and financial measures were required.

In France, on 17 February 2021, the National Assembly had unanimously adopted a resolution on Long Covid. This text called for a better understanding, knowledge, and treatment of this illness; as well as support for research; development of healthcare protocols; and recognition of Long Covid as an occupational disease. However, on 18 February 2021, a bill on the creation of a Covid-19 victim compensation fund had been rejected. It was crucial to ascertain what measures had been taken by the Council of Europe member States. It was hoped that this discussion would help provide greater visibility to the pleas of these people and support the development of policies as well as their effective implementation to improve the situation. This illness was clearly within the purview of the UN Convention on the rights of people with disabilities. The State Parties of this Convention had to ensure the compliance of their policy and practice with their commitments.

Mr Roine pointed out that an international definition and diagnostic criteria for Long Covid were still in preparation by the World Health Organization. Long Covid was defined a little bit differently by the US National Institute of Health, which said that symptoms included fatigue, shortness of breath, brain fog, sleep disorders, fever, gastrointestinal symptoms, anxiety, and depression. Symptoms could persist for months and could range from mild to incapacitating and could arise well after the infection. The UK National Institute for Health and Care Excellence defined Long Covid as symptoms that continued or developed after the acute Covid-19, including both ongoing symptoms of Covid-19 (from 4 to 12 weeks), and post-Covid syndrome (beyond 12 weeks or more). Also, other names were used such as “post-acute Covid-19” or “chronic Covid syndrome”.

There had been about a hundred of scientific studies published on Long Covid, and at least 15 mechanisms of actions could be listed. There had been meta-analysis of 15 studies on about 50,000 patients that showed that 80% of SARS-Cov-2-positive patients had at least one long-term symptom, of which the most common was fatigue, followed by headache and 55 other symptoms. Those that were most incapacitating for the patient usually originated from the central nervous system, lungs, and cardiovascular system. Long Covid was truly a global challenge. The leading health authorities in US and UK estimated that 10% of all Covid patients would go on to suffer from Long Covid, and that there were two million of those patients in the UK, 10 million in USA, and over a hundred million worldwide. Long Covid had been defined as a major health threat by both US and UK authorities, and the economic impact of Long Covid in the US alone had been estimated at four thousand billion US dollars over the next ten years. In 2021, the US government had invested one and a half billion US dollars in research on Covid-19 and there had been recent developments, most notably President Biden’s statement that Long Covid patients might qualify for support under the Americans with Disabilities Act.

Most Long Covid symptoms were mild, and patients recovered, but they sometimes persisted and became cyclic. Brain and cardiac imaging had shown structural and functional changes. Scientific knowledge remained fragmented. There had been some studies on the risk factors, but more needed to be learned about prognosis and long-term outcomes. There had been some structural and functional changes in brain, cognitive decline had been described. There had been an increase in other diseases, including Alzheimer's disease. There was a need for specific therapies instead of symptomatic treatment. Proper organisation of care was important as well.

Differences in methodologies, targeting populations principles, follow-up time, and definition of disability, led to conflicting results. Large population surveys were mainly based on questionnaires, and low response rates were most likely associated with the bias in those studies. The new diagnostic codes were not widely used, and therefore registered studies were unreliable. To avoid discrimination against Long Covid patients, awareness had to be raised among healthcare professionals. Relevant legislation had to be developed. Care guidelines and multidisciplinary clinics were crucial. Patients’ organisations should be more closely involved.

The national Long Covid expert panel of Finland comprised 14 members with wide coverage of public health issues, including infectious diseases, neurology, psychiatry, cardiology, internal medicine, critical care, pulmonology, paediatric medicine, and sleep medicine. Panel duties included systematic analysis of data and studies in order to form a national consensus on definitions, diagnostic criteria, diagnostics, treatment, rehabilitation, and healthcare, as well as to develop recommendations for decision-makers.

Mr Altmann pointed out that Long Covid was a designation that had been proposed by the people affected by this condition. This condition followed SARS-CoV-2 infection and was known from the first few months of the pandemic in 2020. Much of the research on Long Covid had focused on epidemiology and estimation of caseload. While this was vital, it also provoked disagreements, largely due to the difficulties inherent in collecting the data. The "self-reporting" by sufferers was all that had been available until objective clinical diagnostic tests were developed and agreed. Yet, the nature of such reporting led sceptics to consider this condition subjective or psychosomatic. The uncertainty of the Long Covid validation often was overlaid on top of lack of record for Covid-19 infection. A minimal estimate of infections stood at 220 million, although many had no confirmation through PCR or antibody testing. Working with the now widely agreed estimate that 10-20% of infections lead to persistent symptoms suggested a global pool of 20-40 million Long Covid sufferers. The greatest uncertainty came from the fact that studies tended to have high confidence when counting those suffering persistent symptoms at 8 or 12 weeks after acute infection, but the datasets were poor at counting the longer-term timeline to recovery. There was a sense that some recovery must occur since numbers seemed to be somewhat lower at 12 or 18 months than at 3 months. Nevertheless, the group of people with little recovery at 12-18 months was extremely large. Better predictive estimates of the timeline to recovery were needed.

Meta-analysis of Long Covid reports from around the world, with a highly reproducible convergence around a set of common symptoms, confirmed that this was a consequence of infection by this virus, not skewed to those from any specific culture or healthcare system. Early on, there had perhaps been some confusion as to whether one was looking at the body's recovery to serious illness, and hospitalisation. This could have been a part of the story, but it was important to note that Long Covid cases were scattered across the spectrum, from those who suffered asymptomatic infections, to mild, severe, or near-fatal episodes, with or without hospitalisation. It was unclear at that moment whether, for a disease that could present itself with such heterogenous symptoms, it was useful to consider a unifying mechanistic hypothesis. A set of working hypotheses had been put forward to explain causality of Long Covid. Possible mechanisms ranged from direct tissue damage at sites such as blood vessels, lungs, heart, kidney, due to cytopathic damage and subsequent scarring, to ongoing effects of a persistent virus reservoir; perturbation of the regulatory balance between immune subsets; and the induction of new autoimmune responses. These hypotheses were currently under investigation. It was hoped that this research would help develop diagnostic tests and insights into therapeutics.

Case-counting, testing and therapeutics were important because this was a serious additional healthcare problem – one that could torment our societies long after the vaccination rollout. A large new pool of chronic disease sufferers meant that lives were destroyed, people were left out of work, and an enormous pull weighed on healthcare provision. This had implications for employment law and chronic disability support. Healthcare workers who were infected occupationally were over-represented among Long Covid sufferers.

Many countries had been proactive in trying to put Long Covid clinics in place. However, for such efforts to be useful in the long term, there was a need to estimate patient numbers, provisions of adequate numbers of clinicians, and budgets to pay for their training, tests, and auxiliary staff. Many Long Covid clinics had to "build the plane while flying." For a highly variable, relapsing, and remitting disease process that could span a requirement for clinical expertise in respiratory disease, cardiology, neurology, psychiatry, vascular medicine, renal medicine, and rheumatology, a lot had to be done to establish an integrated care pathway. Most importantly, in the absence of further research findings, it was still unclear which tests and which therapeutics were most useful. These questions needed to be answered rapidly, otherwise it was not possible to make best use of such clinics.

Management of acute Covid-19 infections had imposed such an onslaught on our lives, healthcare provision, and economies, that it was tempting to ignore Long Covid as less of an emergency and "to cross that bridge when we got to it". Now was the time "to cross that bridge" and to tackle this problem.

Ms Wonner asked whether it was possible to establish a link between the absence of early treatment and Long Covid. Was there any data available on this? Many people believed that early steroid therapy or antiviral therapy could be beneficial.

Mr Altmann responded that it was still too early to judge whether it was beneficial to use such treatments.

Mr O'Reilly said that he was aware of some anecdotal cases of Long Covid. It was difficult to diagnose Long Covid as a standalone condition, and not as an exacerbation of a pre-existing condition. How could this distinction be made?

Mr Leite Ramos shared his own experience of having had Long Covid, with severe fatigue. He had undergone many tests. It had taken several months to determine that his chronic fatigue was associated with Covid-19. Fatigue treatment had finally been prescribed. Many other people might have a similar experience. Rapidly established diagnosis and appropriate treatment were needed.

Mr Altmann acknowledged the difficulties. Agreement on diagnostics needed to be reached, especially on marker-based tests. Diagnostic criteria based on biomarkers were supposed to be routine. Until this was the case for Long Covid, access to care, employment and disability benefits was difficult to ensure. New diagnostic methods were needed.

Mr Roine agreed that new diagnostics were needed. However, it might not be possible to diagnose Long Covid based on clinical symptoms alone.

Ms Wonner asked whether vaccination protected against Long Covid.

Mr Roine responded that there was evidence that vaccination reduced the risk of Long Covid at least by half.

Mr Altmann agreed. There were convincing studies showing that 10-20% of Covid patients were expected to have Long Covid, while after vaccination the numbers were lower.

Ms Trastour-Isnart shared personal testimony of having had Long Covid, with migraines and muscle pain that had reduced in intensity after vaccination. Many young and athletic people could not work, walk, or even think properly after having had Covid-19. It was urgent to raise awareness about the situation of the people suffering from Long Covid.

Ms Wonner concluded that humanity was at the beginning of research on Long Covid. It involved multiple symptoms including cognitive and neurological issues. The people affected by it should not be left behind, and health practitioners needed to have a better understanding of this condition. Regretfully, in some cases those suffering from Long Covid were sent home without even being examined. The consequences of such lack of care could be visible for months, or even years.

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[*] All reference to Kosovo, whether to the territory, institutions or population shall be understood in full compliance with United Nations Security Council Resolution 1244 and without prejudice to the status of Kosovo / Toute référence au Kosovo, que ce soit à son territoire, à ses institutions ou à sa population, doit se comprendre en pleine conformité avec la Résolution 1244 du Conseil de sécurité des Nations Unies et sans préjuger du statut du Kosovo.

Committee on Social Affairs, Health and Sustainable Development /
Commission des questions sociales, de la santé et du développement durable

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