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Survey on the Realities of Long-Term Care Lives
- Focusing on Post-COVID-19 Symptoms,
COVID-19 Vaccine Adverse Reactions,
and HPV Vaccine Adverse Reactions, Case of Japan –

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1-155 Uegahara Ichiban-cho Nishinomiya 662-8501, Japan Survey on the Realities of Long-Term Care Lives

- Focusing on Post-COVID-19 Symptoms, COVID-19 Vaccine Adverse Reactions, and

HPV Vaccine Adverse Reactions, Case of Japan -†

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Abstract

This paper presents the findings from interviews conducted with individuals undergoing long-

term care, detailing the realities of their daily lives and highlighting issues within various

systems, including the current social security system. Although there are various reasons one

might require long-term care, this study focuses on individuals affected by post-COVID-19

symptoms that persist after infection, adverse reactions from the COVID-19 vaccine, and

adverse reactions from the HPV vaccine. The reason for examining these aftereffects together

in one paper is that there are many commonalities in the daily life challenges, economic

difficulties, and systemic issues that individuals face as a result of these conditions. This

suggests the need for an integrated analysis of these aftereffects.

Keywords: COVID-19 Vaccine Adverse Reactions, HPV Vaccine Adverse Reactions, Post-

COVID-19 Symptoms

JEL Classifications: I10

† In preparing this paper, I would like to take this opportunity to express my gratitude to those who

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1. Introduction

This paper presents the findings from interviews conducted with individuals undergoing long-term medical care, detailing the realities of their daily lives and highlighting issues within various systems, including the current social security system. The definition of a long-term patient can vary; for example, Nagasaki University defines such individuals as "those currently undergoing treatment for a period of six months or longer, or those recognized as needing treatment for a period of six months or longer. In fact, the author has experienced ongoing health issues since receiving the COVID-19 vaccination, resulting in the approval of medical expense and medical allowance support under Relief System for Injury to Health with Vaccination. Currently, the author attends regular monthly medical appointments and takes prescribed medication. Based on this experience, the purpose of this paper is to shed light on the challenges within various systems, particularly the current social security system, by conducting interviews with seven individuals facing difficulties in daily life due to post-COVID-19 symptoms, adverse reactions to the COVID-19 vaccine, and adverse reactions to the HPV vaccine.

To begin with a definition of terms, according to the Ministry of Health, Labour and Welfare, post-COVID-19 symptoms are described as "symptoms that persist immediately after infection despite the disappearance of infectivity, symptoms that appear anew after recovery, and symptoms that recur after having subsided, for which no other clear cause has been identified." According to Nagao, Hirahata, Kojima, Okada, and Fujisawa (2023), post-COVID-19 vaccine syndrome is described as "symptoms that develop within two weeks after vaccination, significantly impairing function and leading to an inability to attend school or work, thereby causing a withdrawal from daily life."

In a survey conducted by the Ministry of Health, Labour and Welfare, it is noted as "examination of cases with symptoms persisting for 31 days or more," which may be considered one of the criteria for assessment. However, the term "prolonged symptoms" is used instead of "aftereffects." Here, this paper use the term "adverse reaction damage from the COVID-19 vaccine".

¹ Nagasaki University "Certificate of Long-Term Medical Care"

² Ministry of Health, Labour and Welfare, "Q&A on Post-COVID-19 Symptoms (So-called Aftereffects) of COVID-19 Infection." The Ministry of Health, Labour and Welfare's website also includes an explanation from the World Health Organization (WHO), which states: "This condition is observed in individuals who have contracted COVID-19 (SARS-CoV-2), with symptoms lasting at least two months that cannot be explained by other illnesses. It is typically observed three months after the onset of COVID-19 symptoms."

³ Nagao, Hirahata, Kojima, Okada and Fujisawa (2023) .

⁴ Ministry of Health, Labour and Welfare, "Response to Prolonged Symptoms Following COVID-19

Such interviews were also conducted by Yasuoka (2023); however, this new round of interviews was undertaken with the intention of examining this issue over the long term by conducting continuous interviews. ⁵ Through long-term analysis, I aimed to observe chronological changes. In this round of interviews, I also included individuals who have suffered health damage from the HPV vaccine (cervical cancer vaccine). This decision was based on the shared symptoms between those affected by adverse reactions to the COVID-19 vaccine and myself, suggesting that we encounter similar issues in daily life. This paper implies that, although the causes of health issues differ, these individuals face common challenges.

The remaining structure of this paper is as follows: Section 2 covers post-COVID-19 symptoms, Section 3 discusses adverse reactions from COVID-19 vaccination, and Section 4 addresses adverse reactions from the HPV vaccine. Each section provides details of interviews with individuals experiencing health issues and explanations of the relevant systems. Section 5 is the conclusion.

Vaccination".

⁵ Yasuoka (2023).

2. Post-COVID-19 Symptoms

Case A

A woman in her 40s contracted the coronavirus in July 2023. Although the classification of COVID-19 under the Infectious Diseases Control Law was changed from Category II to Category V in May 2023, the possibility of developing post-COVID syndrome still exists after contracting the virus.⁶

When infected with COVID-19, there were symptoms such as shortness of breath, chills and dizziness, a state of unclear memory (commonly referred to as brain fog), and pain in the lungs and chest, making it impossible to go to the hospital. Since there was a COVID-19 test kit at home, it was used and confirmed the COVID-19 infection. Despite this condition, she managed to go to the hospital. However, at the first hospital she visited, she was laughed at and sent home because the tests showed no abnormalities. At the next hospital, tests were conducted, but she was told that they did not treat post-COVID syndrome. She was refused treatment because it was due to post-COVID syndrome. When filling out the medical questionnaire, the hospital staff saw that it mentioned post-COVID syndrome, which led to the refusal of treatment.

Various symptoms have continued up to the present after contracting COVID-19. These include shortness of breath, fatigue, insomnia, and pain. There is also significant difficulty in retaining information (referred to as brain fog), feeling nauseous when looking at text, and challenges in using public transportation. Sensitivity to light and auditory hypersensitivity are also present. In fact, the interview was attended with a family member and arrived in a wheelchair. Currently, symptoms such as insomnia and pain are somewhat managed with medication. However, the recovery is only about 40% compared to when the condition was at its worst.

By 2023, a certain amount of time had passed since the emergence of the COVID-19

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⁶ In the Ministry of Health, Labour and Welfare's "Response after the Transition of COVID-19 to a Category V Infectious Disease," it is stated that with the change in classification under the Infectious Diseases Control Law from Category II to Category V, measures such as "not requiring uniform infection control measures by the government" and "not mandating self-restraint from going out for COVID-19 positive individuals and close contacts" were implemented.

⁷ In Category II, the medical institutions where COVID-19 patients could seek treatment were limited, but in Category V, it is explained in the Ministry of Health, Labour and Welfare's materials that treatment is available at a wider range of medical institutions (refer to the Ministry of Health, Labour and Welfare's "Response after the Transition of COVID-19 to a Category V Infectious Disease"). However, in reality, there are hospitals where patients cannot receive treatment for post-COVID syndrome.

pandemic, and several news articles on post-COVID syndrome began to be reported.⁸ The person thought that understanding of post-COVID syndrome among doctors had progressed, but there were still not many doctors who would treat post-COVID syndrome. This situation is similar to that of health issues after receiving the COVID-19 vaccine. Because it is a condition that is not yet widely known, the number of doctors who can provide treatment is inevitably limited. Additionally, in hospitals of a certain scale, changes in primary physicians make it difficult to be consistently seen by the same doctor, which is another factor preventing the condition from being properly understood. In actual medical consultations, due to severe forgetfulness associated with brain fog, it was necessary to bring notes to explain the symptoms. Since the symptoms were often not well understood, there were cases where a psychological cause was diagnosed. Currently, the person visits orthopedic clinics and post-COVID outpatient departments where there is understanding of the symptoms and undergoes rehabilitation.

Regarding medical care, the person does not receive treatment under private medical care but mainly through insurance-covered medical treatment. In the case of insurance-covered treatment, medical expenses are determined by medical fees, with a 30% out-of-pocket cost, and the high-cost medical expense benefit applies. Additionally, as a single mother, the burden of medical expenses is reduced by the maternal and child healthcare system. However, once the child graduates from high school, this system can no longer be used, leaving concerns about future medical expenses.⁹

Regarding daily life, up until now, the person was able to do home-based work such as piecework and household chores, but after contracting COVID-19, they have been in a state where they lie down most of the time except for using the bathroom and eating, and even taking a bath requires significant effort. Under such circumstances, an independent lifestyle has become difficult, and household chores such as meal preparation are being carried out by her sister. Since the infection, she has not been able to work and is covering living expenses with a survivor's pension. However, as previously mentioned, with her child graduating from high school, the amount of the survivor's pension will decrease, creating anxiety about

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⁸ There is an NHK report titled "COVID-19: Prolonged Aftereffects, What Are the Symptoms? How Long Do They Last? A National Survey Shows...". The Ministry of Health, Labour and Welfare has also issued materials such as "Post-COVID Conditions (So-Called Aftereffects) of COVID-19" that provide information on the status of post-COVID syndrome and balancing treatment with work. However, it cannot yet be said that the issue of post-COVID syndrome is fully recognized.

⁹ For example, in Nishinomiya City, there is the "Medical Expense Assistance Program for Single-Parent Families," in which the city covers part of the out-of-pocket medical expenses (refer to Nishinomiya City "Medical Expense Assistance Program for Single-Parent Families").

sustaining her future life.¹⁰

She consulted with the city office about using disability welfare services to assist with daily living. ¹¹ Although the term "post-COVID syndrome" exists, it does not have an official disease name, making it difficult to access services. The wheelchair currently being used is one from 20 years ago. Considering the current physical condition, a reclining wheelchair is needed, but it is very expensive, making it difficult to purchase. While assistance is available for purchasing if one has a physical disability certificate, obtaining this certificate requires visiting a hospital capable of preparing the necessary documents for the application. However, under the current circumstances, accessing such a hospital is not easy, and the application process has not yet been initiated. ¹²

There are two main wishes for the current life situation. One is to receive disability recognition to obtain assistance for purchasing a wheelchair and support for daily living. The other is employment within a disability quota. Although the current health condition limits the ability to work, considering the future reduction in survivor's pension benefits and an increase in medical expenses, it is necessary to work and earn an income.

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¹⁰ For example, the recipients of the basic survivor's pension are defined as a "spouse with children" or "children." Here, "children" refers to those "up to March 31 of the fiscal year in which they turn 18, or those under 20 years of age who are in a condition classified as Grade 1 or Grade 2 under the disability pension criteria" (refer to Japan Pension Service "Basic Survivor's Pension (Eligibility, Recipients, and Pension Amount)").

¹¹ For details on disability welfare services, refer to the Ministry of Health, Labour and Welfare's "About Disability Welfare Services."

¹² For example, in Amagasaki City's "Provision of Assistive Device Expenses (for those aged 18 and over)," it is explained that individuals who have been issued a physical disability certificate are eligible to receive devices categorized as "assistive devices" and "daily living equipment," which include wheelchairs as one of the eligible items.

Case B

A woman in her 30s contracted the coronavirus in August 2023. During the illness, she experienced symptoms such as a fever of 38°C, a sore throat, and insomnia. Even after about 10 days had passed since the onset, she continued to feel unwell. She wanted to visit the hospital again for further examination, but the hospital where she initially received treatment for the coronavirus refused her request, stating that her symptoms, such as fever, had already subsided. As a result, she was in a situation where she had to receive daily IV drips at a nearby clinic. The list of hospitals published by the prefecture of residence included facilities capable of examining post-COVID-19 symptoms, and although she visited one of these hospitals, the response was inadequate. Although the company she worked for recommended that she go to a large hospital, she was still unable to receive sufficient examination there. Due to the fact that post-COVID-19 syndrome is still an unknown condition, effective treatment methods have not been established, and even if there are treatments that could alleviate the symptoms, it is possible that such methods are not being shared among physicians. She had originally been attending a gynecology clinic and had hormone tests conducted there, but no abnormalities were found. Although she requested a referral letter from that hospital to visit a hospital specializing in post-COVID-19 treatment, she was unable to obtain one.

She is currently receiving treatment at the Kampo (traditional Chinese medicine) department of a general hospital that prescribes herbal medicine and has been attending since October 2023 to the present. Regarding her current condition, she is sensitive to seasonal changes; she feels well in spring, but her condition worsens in warmer seasons. Her current symptoms include joint pain, muscle pain, a sense of heaviness, fatigue, and the need to lie down frequently. Due to these symptoms, which cause fatigue, she takes precautions when traveling and moves only after assessing her condition. Initially, her family did not understand these symptoms, but over time, they have come to understand.

After contracting the coronavirus and experiencing post-COVID-19 health issues, she requested a leave of absence from her company. The company reluctantly accepted her request. While on leave, she received contact from the company every 10 days and had to explain her symptoms each time. The company's response seemed to question why she was taking leave, and they did not fully understand her symptoms, which she described as distressing. Following her leave of absence, she resigned from her position. She applied for sickness benefits after her resignation and received the payment after some time, but it only covered less than two months, which was a short period. The reason for this was related to the duration of her enrollment.¹³ At her previous workplace, she was laid off during the COVID-

¹³ According to the "Information on Injury and Sickness Allowance" from Japan Health Insurance

19 pandemic. At that workplace, she was employed outside the period during which the Employment Adjustment Subsidy was provided, and as a result, the situation necessitated her dismissal. Consequently, the payment of sickness benefits was terminated with her recent resignation. She left her previous job at the end of March, and the company she most recently worked for had April 1st and 2nd as a weekend, resulting in her employment starting on April 3rd. Due to this period of unemployment, she was deemed not to have met the required insured period, which made her ineligible to receive sickness benefits after her resignation.

The basic unemployment benefit from employment insurance that she was receiving while unemployed has also ended. She currently lives with her family. Financial issues in her daily life are not significant. However, she wishes to work and is utilizing long-term care consultations at Hello Work (Public Employment Security Office), but there are no job listings for remote work that she can do under her current condition, resulting in a mismatch between available jobs and her needs.¹⁵

She is currently considering applying for disability pension benefits. Her current monthly medical expenses are approximately 5,000 yen. When she was visiting acupuncture and osteopathic clinics, her expenses ranged from 5,000 to 10,000 yen. Although these treatments provided temporary relief, they did not result in fundamental recovery. Social reintegration for patients with post-COVID-19 symptoms is a significant issue, and she seeks understanding and support. Her request to society is for more flexible employment options that would enable her to work.

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Association (Kyokai Kenpo), receiving sickness benefits after resignation requires "a continuous insured period of one year or more up to the day before the loss of insured status (resignation date)." Additionally, regarding the sickness benefits, there were two days during which she neither visited a medical institution nor took medication, and as a result, those two days were not eligible for payment. This was because she could not prove that she was ill on those days. The reason for having days when she could not visit a medical institution was that she did not know which medical institution to go to, and her poor health made it impossible for her to even attend appointments.

¹⁴ Ministry of Health, Labour and Welfare, "Employment Adjustment Subsidy (Special Provisions Due to the Impact of COVID-19)."

¹⁵ According to the Hyogo Labor Bureau of the Ministry of Health, Labour and Welfare, the long-term care consultation service is a support desk for individuals who have left or changed jobs due to long-term medical treatment.

3. HPV Vaccine Adverse Reactions

Case A

There are commonalities between adverse health effects following HPV vaccination and those following COVID-19 vaccination. Although there are people who suffer from health issues after receiving the HPV vaccine, it is not frequently covered in the news and rarely comes up in conversations. Similarly, while there are people who experience health issues after receiving the COVID-19 vaccine, it is also not frequently reported in the news or discussed in conversations, highlighting many common points. The HPV vaccine is targeted at women and has an age limitation for eligibility. 16 People who believe that HPV is unrelated to them, such as men, tend to show little interest. The interviewed person explained that it is important for those affected to voice their experiences. The interviewee mentioned that hearing news about the adverse effects of COVID-19 vaccination made victims of HPV vaccination feel even more frustrated. The author personally regrets that, had they researched the health effects of the HPV vaccine more thoroughly, they might have avoided experiencing adverse effects from the COVID-19 vaccine. Although HPV vaccination was part of the routine immunization program, the government temporarily refrained from active recommendations. However, as there were no particular safety concerns, it became a target for active promotion starting in April 2022.¹⁷ However, while there are indeed individuals who experience health issues after vaccination, it is hard not to feel a sense of discomfort regarding the government's conclusion that there are no particular safety concerns.

The person interviewed received the vaccine in 2012 at the age of 14. Post-vaccination symptoms included headaches and body pain, but they were initially thought to be due to the fatigue from studying for entrance exams. In 2013, what had previously been positioned as an emergency promotion project became part of the routine immunization program, and she received the third dose. After the vaccination, she experienced symptoms such as fatigue and severe pain in her legs, which persist to this day. After graduating from university, she secured a job at the city hall under a disability employment quota but was forced to resign due to her poor health. During her employment, it was difficult for her to work satisfactorily due to taking leaves of absence and hospitalizations. In 2021, she faced severe pain throughout her body, was bedridden, and experienced extreme fluctuations in her physical condition, a

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Men can also receive the vaccine if they wish to do so. Reference: Tokyo Metropolitan Health and Medical Bureau, "HPV Vaccination for Men."

¹⁷ Reference: Ministry of Health, Labour and Welfare, "Important Notice for Girls in Grades Equivalent to 6th Grade to 1st Year of High School and Their Guardians (Summary Version)."

Reference: Sukagawa City, "Relief for Health Damage Caused by the Emergency Promotion Project for Cervical Cancer Prevention Vaccination."

situation that continues to this day. Her health has progressively deteriorated and improved repeatedly, leading to a prolonged condition. During medical consultations, she was at times diagnosed by doctors as having psychosomatic symptoms, and it was challenging to find a doctor who would provide thorough care.

Relief System for Injury to Health with Vaccination has been certified, and she receives coverage for medical expenses and medical allowances. Additionally, she receives a disability pension of 60,000 yen per month under the public pension system. Her daily life is supported by living with her parents, who take care of her needs. She has obtained a disability certificate, and her medical expenses are covered by city policies, making them free of charge. Although there is a disability pension within Relief System for Injury to Health with Vaccination, the interviewed person has not been able to apply due to issues such as the high barriers to application, including the need to gather medical records. She hopes for services that support the application process. She relies on assistance and support from her family to maintain her daily life, and even when visiting the hospital, her parents accompany her. She constantly worries about what would happen if her parents were no longer able to help or became unable to move, leaving her with an uncertain future.

¹⁹ For example, Nishinomiya City "Medical Expense Subsidy Program for Persons with Disabilities" provides an explanation regarding the reduction of medical expenses.

4. COVID-19 Vaccine Adverse Reactions

Case A

A woman received the COVID-19 vaccine in August 2021, and her previously active and healthy daily life drastically changed. On the third day after the vaccination, she started experiencing dizziness and headaches, and two weeks later, she developed symptoms of light sensitivity. She visited a neurosurgeon and underwent CT and MRI scans, but no abnormalities were found. She also went to four ophthalmologists and one otolaryngologist, all of whom diagnosed her vision and visual field as normal. 20 She went to a neuroophthalmologist as the sixth specialist and was diagnosed with photophobia, which was believed to be a side effect of the vaccine.²¹ Six months later, her condition worsened, and she developed a syndrome of persistent difficulty in opening the eyes. A syndrome of persistent difficulty in opening the eyes has no established treatment, and there are cases where some people improve only through non-insurance-covered medical care. Unlike insurance-covered medical care, non-insurance-covered medical care does not have prices determined by medical fees, and patients must bear the full cost, posing a significant financial burden. A syndrome of persistent difficulty in opening the eyes is a condition where even a small amount of light causes severe glare, intense eye pain, and is accompanied by symptoms such as headaches, dizziness, nausea, and fatigue.²² For this reason, custom-made blackout curtains have been installed to completely block outside light from entering the home, and blackout tape has been applied to appliances and other items. However, complete blackout is not possible, so sunglasses or goggles are needed even inside the house. Additionally, expenses have been incurred to separate living spaces from the rest of the family. These costs alone have amounted to over one million yen. Furthermore, an application for Relief System for Injury to Health with Vaccination was submitted in April 2023, and the result is currently pending.

The term "a syndrome of persistent difficulty in opening the eyes" is not commonly used, and there is a current situation where such symptoms are difficult for others to understand.

²⁰ CT and MRI are devices used to examine the inside of the body to check for any internal abnormalities.

²¹ According to the "Symptom Search" section of the Japan Ophthalmological Society's Public Interest Incorporated Foundation, photophobia refers to a condition in which even normal levels of brightness feel excessively bright, making it difficult to keep the eyes open.

For information on ocular motor apraxia, refer to "The Inconvenience of Daily Life Without Relief—Concerning a Syndrome of Persistent Difficulty in Opening the Eyes " by Masato Wakakura on Jiji Medical. In that document, it is pointed out that there is an issue where, since there are no abnormalities in visual acuity or visual field and it is not an eye disease, it is not recognized as a visual impairment. As a result, this poses a problem when applying for a disability certificate or receiving disability pension benefits.

Additionally, since it is not recognized as a visual impairment, receiving disability pension benefits is extremely challenging. The condition of a syndrome of persistent difficulty in opening the eyes developed after receiving the vaccine, but initially, any connection to the vaccine was denied, and there were instances where home visits for medical care were refused due to the house being kept dark with blackout curtains. Furthermore, despite experiencing severe eye pain triggered by light exposure, the situation required an initial visit to a hospital even for home medical care.

To describe the current symptoms, although there has been some slight improvement compared to when she needed to use double-layered blackout curtains to keep the house completely dark just to live, blackout curtains are still necessary, and she still needs to wear goggles indoors to block out light. Because the house is kept dark, she cannot see my family's faces. She is unable to go outside due to the light, and even having sunlight touch my skin causes me to feel unwell.

Regarding the disability pension, she considered applying not for a syndrome of persistent difficulty in opening the eyes but for chronic fatigue syndrome before mental health conditions. However, obtaining that diagnosis and having the necessary documents prepared requires going to the hospital, which is extremely difficult for her. Although she requested home medical care, it was not accepted, and therefore, she has not been able to submit the application. She is unable to do any household chores and relies on a helper. The burden on her family is significant. She applied for a disability certificate but has not obtained one. Currently, I am using disability welfare services based on a disability support classification for mental health conditions.²³

Regarding medical expenses, insurance-covered medical care previously cost about 20,000 yen per month when the symptoms were severe, but currently, with home nursing care only once a month, the expenses for insurance-covered medical care have decreased compared to before. However, expenses for non-insurance-covered medical care still amount to 60,000 to 70,000 yen per month, and when including supplements, the total expenditure reaches 100,000 yen per month.

Regarding living expenses, being a dual-income household originally helped avoid extreme financial difficulties. Before the COVID-19 vaccination, she supported herself through self-employment, but currently, working is difficult. There are no mortgage or housing payments, which has helped prevent them from falling into poverty and made it possible to maintain their life. However, her husband's health deteriorated from balancing work and caregiving,

²³ There is a detailed explanation of disability welfare services in the Ministry of Health, Labour and Welfare's publication, "About Disability Welfare Services."

leading to a temporary leave of absence. Although he has since returned to work, this situation highlights the significant burden that family caregiving entails. When asked at the end of the interview what she hope for from the social security system, her answer was that she wants to be recognized for obtaining a disability certificate and receiving disability pension for a syndrome of persistent difficulty in opening the eyes.

Case B

A man in his 20s received the first and second doses of the vaccine in 2021 and the third dose in February 2022. Two days after the third vaccination, he experienced symptoms such as a heavy feeling in the body, fatigue, a sense of faintness, head heaviness, brain fog, palpitations, and muscle pain, which led him to leave work early that day.²⁴ Although he experienced slight insomnia after the first and second doses, he attributed it to his night shift work and thought it might be related to that. At the time, he did not consider the possibility that the vaccine was the cause.

His poor health continued, leading him to take a leave of absence, which lasted for three months. After that period, he was treated as having resigned from his job. He currently holds a mental disability certificate.²⁵ He is also utilizing disability welfare services. He receives a disability pension for mental health, amounting to approximately 50,000 yen per month. Since it is paid every two months, he receives around 100,000 yen every two months.²⁶ Additionally, through Employment Continuation Support Type A, he earns an income of 80,000 yen per month, which, combined with his disability pension, results in a total monthly income of 130,000 yen.²⁷ His living situation is manageable due to living with his parents. Living alone is difficult due to financial constraints. It should be noted that the recognition for receiving the disability pension was not related to side effects from the COVID-19 vaccination. He was diagnosed with conditions such as adjustment disorder.

In addition to the aforementioned issues, the third vaccination led to various other symptoms. Specifically, these included light sensitivity, visual discomfort, worsening insomnia, and cough-variant asthma. Medications were prescribed for pain and other issues. During a visit to a certain psychiatric clinic, there was an abrupt discontinuation of all previously taken

²⁴ In the NHK article "Post-COVID-19 Sequelae: What Is 'Brain Fog'? Symptoms and rTMS Treatment," brain fog refers to a condition where it feels as though a fog has settled in the brain.

The National Center of Neurology and Psychiatry, National Institute of Mental Health's information site "Disability Certificate and Disability Pension" provides explanations on various support measures available through obtaining a disability certificate.

There are two types of disability pensions: the Disability Basic Pension and the Disability Employees' Pension. Regarding disability grades, the Disability Employees' Pension can be received even at grade 3, but the Disability Basic Pension is only available for grade 2 or higher. Refer to the Japan Pension Service "Disability Pension" for more information.

²⁷ For information on employment support for people with disabilities, refer to the Ministry of Health, Labour and Welfare's publication, "Status of Employment Support Measures for People with Disabilities." Employment Continuation Support Type A is described as providing "employment opportunities through the conclusion of employment contracts and opportunities for productive activities to individuals who find it difficult to be employed by regular companies but are capable of working under an employment contract."

medications, which subsequently led to further health deterioration, including complete insomnia.²⁸ It is said that it is unclear whether these symptoms are due to side effects from the vaccine or the result of sudden drug discontinuation.

Even when he told the psychiatrist that his health had deteriorated due to the vaccine, he was not taken seriously. He was told that there would likely be no abnormalities found in tests and that it was considered a psychosomatic issue. Believing that his condition might improve if he separated from his family and rested alone, he chose to undergo treatment in a hospital, but his condition did not improve. He mentioned that, due to working in the caregiving field, he felt social pressure to get vaccinated.

He is currently continuing treatment primarily through insurance-covered medical care and is utilizing Medical System for Services and Supports for Persons with Disabilities.²⁹ In daily life, he feels a decline in physical strength and becomes fatigued easily, but he has recovered about 90% from the most severe state of his symptoms. However, due to the decrease in physical strength, working full-time is currently difficult. Additionally, his heart problems persist.

He stated that he does not plan to apply for Relief System for Injury to Health with Vaccination. The reasons include not feeling inclined to apply in the first place, the negative views expressed by doctors, the complexity of understanding the system, and the difficulty of gathering the required documents. His hopes for society include that individuals who experience health issues after vaccination are not diagnosed with psychosomatic conditions simply because the cause is unclear, that more psychiatrists understand the side effects of vaccinations, and that there is greater understanding in the workplace regarding such issues.

The interview concluded at that point but was later followed by an additional interview. The content of the follow-up is as follows. After further tests, he was diagnosed with atrial fibrillation. He had already experienced palpitations and arrhythmia following the vaccination, and it is believed that these symptoms progressed. Atrial fibrillation is a condition that, if left untreated, can lead to serious health issues such as stroke and other life-threatening complications.³⁰ The symptoms appeared some time after the vaccination. He feels that the

²⁸ It is known that abruptly stopping the use of benzodiazepine drugs, including sleeping pills, can lead to various symptoms, and it is generally recommended to taper off these medications gradually. Refer to Tsukizaki (2023).

Medical System for Services and Supports for Persons with Disabilities is a system designed to reduce the burden of medical expenses, such as for outpatient psychiatric treatment. Refer to the Ministry of Health, Labour and Welfare's "Medical System for Services and Supports for Persons with Disabilities " for more information.

³⁰ Refer to the Hyogo Medical University Hospital's "Disease Guide: Cardiology - Atrial Fibrillation" for

symptoms are progressing, and although he is currently continuing with medication, he is considering surgery in the future. Initially, he did not think about applying for Relief System for Injury to Health with Vaccination, but he is now considering applying in regard to the atrial fibrillation. He faces each day with uncertainty, not knowing whether he will recover.

more detailed information.

Case C

A woman in her 40s received her first dose of the Pfizer vaccine in June 2021, with the second dose in July. After the first dose, she experienced symptoms such as drowsiness, but various symptoms appeared after the second dose. Within 30 minutes of the second dose, she experienced numbness in her right leg, drowsiness, a scratchy throat, and fatigue. About two and a half hours later, she developed itching and a rash on her left hand, and after seven and a half hours, a rash appeared on her left calf. Although the rash disappeared within 10-15 minutes, she later experienced severe abdominal pain and diarrhea. Additionally, on the night of the vaccination, she had uncontrollable sneezing, muscle pain throughout her body, a fever of 37.6°C, severe pain in her right arm, and such intense pain that she could not turn over in bed. The following morning, she still had a low-grade fever, headache, and sore throat. Although her temperature temporarily returned to normal, she experienced pain under her right armpit in the afternoon, followed by another fever. Although the fever subsided and she returned to work, pain in her right arm and under her right armpit persisted. However, by the afternoon, she began to sweat profusely, and after work, she experienced symptoms of anaphylaxis, including hives, shortness of breath, and itching of her lips and eyelids.

She went to the emergency department, where she was diagnosed with anaphylaxis while experiencing symptoms such as a low-grade fever, pain in her lower limbs, and a sense of lightheadedness. She did not expect the COVID-19 vaccine to be the cause. She received an IV drip and an anti-itch medication and thought these treatments would resolve the symptoms, but her condition did not improve easily. Although she wanted to seek treatment at another hospital, that hospital refused to accommodate her. Even when she told the doctor that her health issues were related to the COVID-19 vaccine, they did not believe her, refused to listen, and made dismissive comments, stating that there was no connection between the vaccine and her condition. Additionally, a nurse told her that she should be grateful for receiving any medical attention.³¹ When she went to the vaccination doctor, her request for an examination was initially refused. After visiting the emergency department, she also experienced symptoms such as a burning sensation on the tip of her tongue, discomfort in her lower lip, a scratchy throat, and a dislodged dental filling.

When she consumed dairy products, her condition worsened. The health center she consulted explained that her reaction to the vaccine was due to an existing intolerance to dairy

³¹ For information on doctor harassment, refer to "What is Doctor Harassment? Introduction to Consultation Outlets for Victims" on Bengoshi JP. Additionally, refer to the Ministry of Health, Labour and Welfare's Japan Medical Association Medical Law Relations Review Committee's report titled "Reexamination of the Legal Aspects of the Doctor-Patient Relationship – Focusing on the Division of Roles between Government Regulation and Doctors' Self-Regulation."

products. If there had been information about dairy intolerance in the consent form at the time of vaccination, she could have chosen not to receive the vaccine, potentially avoiding the various symptoms that followed.

Currently, for treatment, she travels to a city a bit farther from where she lives to receive B-spot therapy.³² She undergoes this treatment once a month at a cost of 440 yen. Additionally, she visits an osteopathic clinic once a week for treatment of post-vaccine symptoms. Since this treatment is not covered by insurance, she pays 2,000 yen out of pocket. Her current symptoms include a burning sensation in her lower lip and the tip of her tongue, a feeling of pressure in her throat, and an overall worsening of her pre-existing allergy condition. Furthermore, she can no longer take painkillers such as Calonal and Tramadol, and she has become unable to receive the influenza vaccine.

When she visited the hospital's emergency department for dental treatment and reported abnormal reactions to the medication used during the procedure, the doctor became angry with her. Even when she submitted a written complaint to the hospital, it was ignored. This situation is considered doctor harassment (referred to as "doctor harassment" or "Doc-hara"). Additionally, before receiving her first vaccine dose, she was told by a neurosurgeon to ask questions whenever she had concerns in her daily life. However, when she did ask questions about the vaccine, the doctor reacted angrily. At another clinic, when she requested an explanation about the vaccine, the response was incomprehensible, leaving her unable to understand. She expressed that these experiences made her doubt whether doctors truly have sufficient knowledge about the vaccine. Ultimately, she found that no hospitals would treat post-vaccine symptoms, and she was sent to a psychiatric department, with her condition attributed to psychological causes.

Before receiving the vaccine, she worked at a nursing facility. However, after experiencing health issues following the vaccination, she began to face bullying at work, including being ignored, having items thrown at her when handed over, and intentional acts of harassment. This forced her to resign. Before the vaccination, she was physically active to the extent of running marathons to improve her fitness. After resigning, she has been living primarily on unemployment insurance benefits and withdrawing her savings. Due to her workplace circumstances, she has not received any injury and sickness allowance.

Recently, discussions about post-vaccine symptoms have been taken up in parliamentary sessions, allowing for more open conversations on the subject. Previously, it was difficult to talk about health issues caused by the vaccine, and only a handful of people were understanding. The interviewee lives in a rural area and is currently still unemployed. Due to

³² Refer to Tanaka (2020) for information on B-spot (EAT) therapy.

the neighbors' view of the local community, she continues to live with a sense of social isolation. Moving forward, she plans to take on short-term part-time jobs, specifically desk work, while monitoring her health. She has been unable to work due to post-vaccine health issues, resulting in a gap of over two years in her employment. To prepare for re-entering the workforce, she has been attending events and volunteering.

Case D

A woman in her 30s has been experiencing prolonged health issues after receiving the COVID-19 vaccine. Initially, she was diagnosed with depression and obsessive thoughts. Although she received counseling from a doctor, the doctor was unable to fully understand her symptoms. Other symptoms include insomnia, tinnitus, head noise, and pain. Upon waking up, she feels an overwhelming sense of despair. She also experiences pressure on her face and an unusual sensation on the left side of her facial nerves. However, despite consulting doctors, her symptoms did not improve, and she suffered further due to the doctors' inadequate responses. She encountered not only the doctors' lack of empathy but also the absence of examination beds. Even within the same hospital, there was no coordination among doctors, requiring her to repeatedly explain her symptoms from the beginning. For example, when her attending physician changed, there was inadequate sharing of information regarding the test results she had already received. Although there are hospitals and clinics that could provide beneficial treatment, they are far away, making it difficult for her to access them. In the area where the interviewee lives, a car is essential for transportation. Since driving is difficult for her, accessing medical facilities is limited. Despite these challenges, she managed to get an appointment at a university hospital. However, appointments at the university hospital come with specific time requirements, making it challenging for her to go alone due to her health issues. The availability of someone to accompany her and her own health condition sometimes make it difficult to adhere to the set appointment times. Even when she receives consultations, her symptoms are often attributed to psychological causes or are simply marked for observation, without any real progress in symptom relief.

She has also undergone treatments such as IV therapy through private medical services, but has not felt much improvement. Unlike insurance-covered treatments, private medical care incurs significant expenses. Additionally, she has encountered what appears to be vaccine-related business practices that exploit post-vaccine symptoms.³³

She is currently in the process of applying for disability pension benefits. If her application is approved, she will be able to secure some financial support for her living expenses. However, she has not yet applied for Relief System for Injury to Health with Vaccination.³⁴ The reason for this is difficulties such as being denied the issuance of medical certificates, which has become an obstacle to her application. Currently, she is mainly receiving acupuncture

33 For information on the vaccine-related business practices, refer to "Beware of the 'After-Effect Business'

Related to COVID-19 Vaccines" by Taniguchi (2021) in Mainichi Shimbun.

Refer to the Ministry of Health, Labour and Welfare's "Relief System for Injury to Health with Vaccination" for more detail information

treatment. She has left her job and is living off her savings.

Lastly, the interviewee has hobbies and participates in related events, but she has faced blatant discrimination, such as being told not to come because of her post-vaccine symptoms.

5. Conclusions

In this paper, we conducted interviews with individuals suffering from post-COVID-19 symptoms, health issues after COVID-19 vaccination, and health problems following HPV vaccination to examine the challenges they face. Although the causes of their health problems differ, common issues have emerged. Here, we would like to enumerate some of them.

The first issue is the difficulty in accessing appropriate medical care. Even after undergoing tests, no abnormalities are found, and the condition is dismissed as psychological. This is a problem the author has also experienced. However, according to materials from Ministry of Health, Labour and Welfare, the Ministry has communicated with each prefecture about reviewing and confirming the medical care system.³⁵ However, in reality, it is difficult to say that these measures have been effectively implemented.

The second issue is the cost of medical care. In some cases, individuals receive treatment not only through insurance-covered medical services but also through private medical services. Unlike insurance-covered treatments, private medical care does not come with a guaranteed outcome and poses a significant financial burden. Additionally, in Relief System for Injury to Health with Vaccination, medical expenses related to private medical services are not covered.

The third issue is the high barriers to accessing social security systems and various support programs. Although there appear to be services and benefits available through such programs, individuals often face problems where they do not meet the conditions required to use them. For example, obtaining a disability certificate for the purchase of a wheelchair, the denial of disability pension despite clear disruptions to daily life, and the limitation of injury and sickness allowance due to the duration of enrollment in public health insurance are some of the challenges faced.

These issues are common to all individuals who struggle to maintain daily life due to health problems. While the issues listed above are only a portion of the challenges faced, addressing them would not only improve the daily life problems of those highlighted in this article but could also lead to improvements for those facing similar difficulties that were not covered here.

Refer to the Ministry of Health, Labour and Welfare's "Establishment of a Medical Care System to Address Individuals with Prolonged Symptoms."

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