

Questionnaire survey on post-vaccination symptoms among peer support group of Finnish families

VACCINATION AND SERIOUS AUTOIMMUNE SYMPTOMS

Abstract

Introduction: Since 2009 especially adolescents have experienced multifaceted serious neuropsychiatric symptoms, which have influenced negatively their everyday life and whose causes have remained unknown in thorough medical evaluations. Thus, most of these patients have ended up to a psychiatric consultation and the families have faced the unfortunate fact that there are no evidence-based treatments available for their seriously ill family members. Consequently, in order to find answers to several open questions a few active members of the Finnish peer support group designed an internet-based questionnaire the results of which we have not been able to get published in any official peer reviewed medical journal.

Methods: The survey was meant for anyone, who had experienced severe post-vaccination symptoms (without any identifiable etiology) in 2009-2017 or to the family of affected persons. The questionnaire included detailed questions (incl. 13 items of multiple choice questions) on health before and after vaccination as well as on given diagnoses, time from vaccination to the onset of symptoms, type, severity and development of symptoms, reporting frequency of suspected adverse reaction(s) to health officials, the geographic distribution of the respondents and financial consequences of the diseases to the families.

Results: The respondents (n=129) represent whole Finland. Adult patients responded the questionnaire by themselves or together with their assistants and parents responded on behalf of their children. Most of the respondents (69%) had been 7-19 year old at the onset of symptoms and 71.3% of the affected had been females. Most of the respondents considered their health excellent (69%) or good (28.7%) poor before falling ill. Only three respondents (2.3%) considered their health poor due to recurrent infections, borreliosis and neuropathy.

All 129 study participants informed to have received all nationally recommended vaccinations. Almost all respondents (126 out of 129) had received swine flu (Pandemrix®) vaccine between autumn 2009 and winter 2010. In 104 out of 129 respondents the symptoms had started after Pandemrix® vaccination; in three participants the symptoms had appeared right after the vaccination. Seventeen respondents had received HPV-vaccine, either Cervarix® (n=15) or Gardasil® (n=2) in 12 of whom the symptoms had started right after the vaccination. In many HPV-vaccinated respondents the symptoms had increased after each booster shot.

The suspected adverse reactions had started in most of the respondents within 2 weeks (37.25) or 2-3 months (27%) of vaccination. In 107 respondents (82.0%) the symptoms had started within 6 months of vaccination with the vaccine (PANDEMRIX®, CERVARIX®, GARDASIL®, IXIARD®) that the respondent suspects as a cause for her/his symptoms.

The most common first symptoms were fatigue or abnormal sleep needs (73.6%), chronic fever (28.7%), muscle and/or joint pain (42.6%) as well as flu like feeling (30.2%). The most common chronic somatic symptoms, still persistent at the time of filling the questionnaire were fatigue (86.8%), low resilience (74.4%), difficulties in memory and cognition (67.4%) and recurrent nightmares (64.1%). In addition ≥ 30% of participants reported sensory hypersensitivity, tachycardia and muscle weakness. Over 50% of the respondents needed assistance in their daily activities and six of them were fully dependent on the others' help. Only 23 respondents (18%) were able to live without assistance or aids. Some had been ill already for 8.5 years during which the severity of their symptoms had varied.

The affected had received numerous symptomatic and disease diagnoses the most common of which were narcolepsy (40.6%), chronic fatigue syndrome (36.7%) and postural tachycardia syndrome (POTS, 24.2%). Typically each respondent had many different diagnoses.

The suspected adverse reaction had been reported to health officials only from 71 respondents (55%). The suspected adverse reaction had been reported to the health official (either by an affected person her-/himself or her/his relative 67.6%), clinician (37.8%) or nurse (16.2%).

These "mysterious" syndromes have driven many families (67.5% of respondents) into significant financial difficulties when they have sought help from private clinics and/or when the other parent has been forced to leave his/her job in order to be able to take care of his/her sick child.

Conclusions: Based on this questionnaire survey the temporal association between vaccinations and the onset of multifaceted neuropsychiatric symptoms seems evident. It is unlikely that this finding would be only a coincidence, since similar cases as observed in this study (around all parts of Finland) have been reported also elsewhere in the world (1-6). The true causality is supported also by the emerging number of research papers published in the medical literature (e.g. 7, 8) according to which aluminum and other vaccine ingredients may cause multi-path autoimmune diseases.

In addition, the well-known low reporting frequency of suspected adverse reactions (< 1-10%) by health professionals (as evidenced also in this survey) may explain (at least partly) why health officials have not recognized the potential safety hazards caused by multiple vaccinations with vaccines that contain neurotoxic ingredients such as e.g. aluminum. Unreported and, thus, unlisted adverse reactions will remain unidentified if the collaboration between patients, clinicians and basic researches is not strengthened.

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1. Introduction

This report is based on an internet-based questionnaire (see the attachment) that was carried out between January and March 2018. It was meant for all those who had fallen seriously ill in 2009-2017 and to those, who suspected their symptoms to be due to vaccination. Each affected person or her/his caregiver replied to the questionnaire anonymously except in four cases for whom the questionnaire was carried out as a phone interview because of their weak health. In the questionnaire the responders replied to the following questions: age, county, gender, health before vaccination / illness, first symptoms and the timing of the symptoms in relation to the vaccination, the vaccination history, the current symptoms, the given diagnoses, reporting of the suspected adverse reaction to health officials and financial consequences of the illness to the family.

Since the end of 2009 children, adolescents and adults have experienced extraordinary severe and disabling symptomatic images associated with dysfunction of autonomic nervous system and / or serious disturbances in sleep / wake state. The most typical symptoms (regardless of age) have been abnormal fatigue, cataplexy, symptom exacerbation caused by physical activity, cognitive impairments, different painful pains, convulsions or other dyskinesia, orthostatic problems and infections.

The diseased, their families and their clinicians have associated the beginning of the symptoms to be related to some specific vaccine. The illnesses have been linked particularly to two vaccines, to Pandemrix® (vaccine against swine flu pandemics) that was offered in 2009-10 to all citizens and to Cervarix® (vaccine against human papilloma virus) that was included in a national vaccination program in autumn 2013. Earlier Pandemrix® was thought to be associated only with narcolepsy. However, later on patients and their treating physicians have realized that the symptom pictures are very similar. Furthermore, similar symptom pictures have been observed also after single vaccinations. Consequently, we accepted responses not only from those who had become sick after Pandemrix® or Cervarix® vaccinations but also from those who had become sick after other vaccinations.

Sick people and their families have found each other gradually via media news, social media and support groups. The common experience has been that it has been difficult to prove that the question is from a vaccine related adverse reaction even though in many cases the symptoms have started right after the vaccination and no other cause has been found to the illness. In addition, there are many families among the respondents in which two or even six family members have become sick during 2009-2010 or afterwards.

The common problem has also been to get adequate examinations and evaluations in order to find the right treatments to increase the ability to function and to return the health. Even severe symptoms (resulting in the patient to be bedridden) have been claimed to be of psychosocial

origin. The affected people and their relatives feel that they have been tried to make guilty for becoming sick and that they have experienced in part inhuman treatment. The problems in social communication may have been great especially between patients (or their relatives) and medical doctors of public hospitals. This has resulted in the fragmentation of the treatment to different sectors and has made the coordination and responsibility of the treatment even more difficult.

With regard to financial support and other grants granted by the society, almost everyone has faced major challenges. For many persons those grants have been denied completely, even though the physicians have estimated that the patient is totally unfit to work or study. Many families have been forced to reimburse all the expenses caused by the illness by themselves. The sick person may have remained totally unfit to work or study and the parent has been forced to stay at home as a caregiver to his/her own child, which has made the family's economic situation unbearable.

Compensatory allowances have been made impossible, because only seldom the causality has been confirmed in physicians' certificates. The reimbursements for narcolepsy patients are inhumanly small and the application procedure has lasted for years. Furthermore, after the so called temporal 'window' the decisions done on the compensatory reimbursements are negative, even after complains. Regarding narcolepsy the question is of a permanent loss of health, so all the support from the society is extremely important especially when the causes for the illness are on the responsibility of the others and not on the affected person's himself/herself.

We hope that this report reaches all those health officials, who are responsible for the follow-up of adverse reactions caused by vaccines and education of the health professionals to recognize adverse reactions. The most important aim, however, is to promote adequate evaluations and treatment of those who are vaccine injured and suspected to be vaccine injured, right diagnostics, accordant treatment and grants compensation.

2. Basic characteristics of the respondents

A total of 129 responders replied to the questionnaire. A place of residence, age range and gender of the responders are presented in tables 1-3.

Table 1. Province, number and percentage of the respondents

Uusimaa	36	27.9 %
Varsinais-Suomi	7	5.4 %
Etelä-Karjala	3	2.3%
Etelä-Pohjanmaa	3	2.3 %
Etelä-Savo	6	4.7 %
Kanta-Häme	10	7.8 %
Keski-Pohjanmaa	1	0.8 %
Keski-Suomi	6	4.7 %
Kymenlaakso	2	1.6 %
Lappi	2	1.6 %
Päijät-Häme	14	10.9 %
Pirkanmaa	23	17.8 %
Pohjanmaa	1	0.8 %
Pohjois-Pohjanmaa	9	7 %
Pohjois-Savo	3	2.3 %
Satakunta	3	2.3 %

Table 2. Age at illness

age range	number	percentage of the respondents
0-6 years	18	14 %
7-13 years	45	34.9 %
14-19 years	28	21.7 %
20-40 years	28	21.7 %
41-65 years	9	7 %
> 65 years	1	0.8 %

Table 3. Gender of the respondents

gender	number	percentage of the respondents
Female	92	71.3 %
Male	37	28.9 %

3. Health before vaccination

Most of the respondents (69%) considered their health excellent before the onset of their illness (table 4). One third of the respondents felt their health good (without any preceding disease). Three persons replied that their health had been bad before vaccination because of recurrent infections (n=2) or chronic borreliosis and radiculopathy (n=1). After vaccination their health had deteriorated further.

Table 4. Health before vaccination (129 responses)

	number	percentage of responders
Excellent	89	69 %
Good	37	28.7 %
Bad	3	2.3 %

4. Vaccination history

All respondents had been vaccinated according to a normal national vaccination program. All respondents were not able to provide accurate information about their vaccinations.

Most of the respondents (96.1%) had been vaccinated with Pandemrix in autumn 2009 or in early 2010. In addition a few persons had been vaccinated concomitantly with another vaccine like for example with MRP-, HPV-, B-hepatitis-, polio- or/and tetanus-whooping cough-diphtheria vaccine (Table 5).

Of the respondents 17 had received HPV-vaccines out of whom 15 has been vaccinated with Cervarix and 2 with Gardasil. Out of those, who had received HPV-vaccines, in 12 respondents the symptoms had appeared right after vaccination. In three responders serious symptoms had started right after Pandemrix vaccination and after HPV-vaccinations their health had collapsed.

In one respondent symptoms had started after booster of IXARD vaccination (vaccine against Japanese encephalitis) on the day of vaccination, in one after seasonal influenza vaccination, in one after tetanus-pertussis-diphtheria and polio vaccination (DTaP-IPV) and in one after diphtheria-tetanus vaccination (DT) vaccination.

Table 5. Vaccine /vaccines, after which the symptom picture started (129 responses)

Vaccine	number	percentage
Pandemrix	103	79.8 %
Pandemrix + Influvac	1	0.8 %
Pandemrix + Twinrix	3	2.3 %
Pandemrix + Cervarix	9	7.0 %
Pandemrix + MPR	3	2.3 %
Pandemrix + Gardasil	1	0.8%
Pandemrix + dT	1	0.8 %
Pandemrix + D-Tap-IPV	1	0.8 %
IXIARD	1	0.8 %
D-Tap-IPV	2	1.6 %
HPV Cervarix	3	2.3 %
Influvac	1	0.8 %

5. The outbreak of the disease

a. The time to the beginning of the first symptoms

Most respondents experienced immediate and violent symptoms appeared soon after the vaccination (37.2%) or at the latest within 3 months of the vaccination (27%). Third most common time interval to the beginning of the symptoms among responders (23%) was 3-6 months after the vaccination (23%). In nine, five and five participants the symptoms started within 6-9 months, 1-2 years and 2-3 years of the vaccination, respectively. In two responders the time to the beginning of the symptoms was over 3 years (table 6).

Twenty-four percentages of the respondents were able to give the exact date for the beginning of their symptoms. The others were able to estimate the time for the beginning of their symptoms in weeks or months precision. The deteriorating disability and new, weird situation may have influenced some respondents, so that they could not recall any longer the exact date when their symptoms had started.

The respondents have described the beginning of their symptoms for instance like this:

“ Right after Pandemrix vaccination”

“ Spiring 2010, after 3rd HPV-vaccination”

“ 31.3.2010 flu like feeling and fatigue”

“ Half year from Pandemrix-vaccination”

“ Everything started from the vaccination day.”

Table 6. The time to the beginning of the suspected adverse reaction (129 replies)

Time	number	percentage
Immediately, < 2weeks	48	37.2 %
2 weeks – 3 months	36	27.0 %
3-6 months	23	17.8 %
6-12 months	9	7.0 %
1- 2 years	5	3.9 %
2-3 years	5	3.9 %
> 3 years	3	2.3 %

b. The first symptoms of the disease

The first symptoms were highly variable, both physical and mental. The first somatic symptoms included allergic reactions, pains, changes in sensory functions, coordination and muscle strength, deterioration of the underlying disease, disorders of thermoregulation, disturbances of consciousness, changes in oxidation and metabolism as well as in blood circulation, disorders related to sleep, cognitive and neuropsychiatric symptoms. HPV-vaccinated persons experienced worsening of the symptoms after each booster.

The persons affected after the vaccination may have experienced weakened immune resistance, i.e. susceptibility to infections, prolonged infections and different infections. The first symptoms occurring after the vaccination have been throat swelling, shortness of breath, allergic reactions and cough. One respondent had experienced pneumonia on the day of vaccination without preceding symptoms.

Pains occurred for instance in head area, eyes, joints and muscles. Pain in joints may have been related to arthritis and later on one physician has diagnosed in one respondent an arthritis, which he (she?) thought was caused by an adjuvant. Sensory disturbances included disorders in vision and hearing problems. Great portion of the respondents experienced as their first symptoms also hypersensitivities like sensitivity to light and noise. The first symptoms that were related to coordination and muscle strength included disturbances in balance, difficulties in moving arms and legs spasticity, inability to function, weakness and problems in walking. The physical stress may have also weakened muscle strengths. The signs for the imbalanced thermoregulation included sweating, recurrent fever and feeling cold as well as the coldness of the peripheral parts of legs. Especially women and girls experienced severe sweating and also hormonal disturbances. The respondents mentioned following symptoms as first signs for their altered level of consciousness: absences, reduced level of consciousness and cataplexy in surprising situations such as laughing. Some of the HPV-vaccinated adolescent women experienced prolonged unconsciousness, seizures and/or jerking.

As possible first signs related possibly to oxidation and metabolism as well as to circulation, the respondents mention restless legs, feeling bad, continuous feeling of hunger, feeling of numbness, stroke and heartbeat.

The reported disturbances related to sleep and sleeping included unintentional falling asleep, tiredness, a broken night's sleep, nightmares, difficulty falling asleep and insomnia. Most respondents described their tiredness as extraordinary need to sleep; in big quantities, in repeated cycles several times a day regardless of environmental or other disturbing factors.

Mood swifts, anger, irritability, anxiety, depression, aggression, hallucinations, fit of rage, OCD-symptoms and fears were mentioned as psychic symptoms. In children these neuropsychiatric symptoms appeared as sudden and radical changes compared to their earlier balanced and tranquil nature.

Disruption of concentration and alertness as well as learning difficulties may have appeared as the first cognitive symptoms. Some have experienced developmental disorders and autistic symptoms. The most typical post-vaccination symptoms reported by the respondents are presented in table 7.

Table 7. Typical symptoms after vaccination

Symptom	number	percentage
Tiredness or abnormal need of sleep	95	73.6 %
Chronic fever	37	28.7 %
Muscle or/and joint pain	55	42.6 %
Flu like feeling	39	30.2 %
Fever, cough, runny nose	29	22.5 %
Difficulty falling asleep	28	21.7 %
Weakening of muscle strength, muscular debity	28	21.7 %
Stomach ache	20	15.5 %
Memory problems	23	17.8 %
Infections or chronic infections	24	18.6 %
Dizziness	24	18.6 %
Heartbeat	21	15.6 %
Limp muscles, muscle dysfunction	21	16.3 %
Paresthesia of the vaccinated arm, numbness, problems in moving	19	14.7 %
Nausea, vomiting	14	10.9 %
Absences, fainting, unconsciousness	14	10.9 %
Continuous headache or migraine	19	14.7 %
Allergies	10	7.8 %
Seizures, twitch, toonic-clonic movements	10	7.8 %
Fits of rage	8	6.2 %
Depression, tearfulness, anxiety	8	6.2 %
Rash	8	6.2 %
Allergic reaction at the site of vaccination	7	5.4 %
Cataplexy	6	4.7 %
Lack of appetite	4	3.1 %
Inflammation of the lymph node	4	3.1 %
Hallucinations	4	3.1 %
Sweating attacks	4	3.1 %
Weight gain /sudden appetite increase	3	2.3%
Arthritis	3	2.3 %
Shortness of breath	3	2.3 %
OCD-symptoms	3	2.3%
Abnormal or long lasting crying (children)	2	1.6 %
Nightmares or horror scenes	2	1.6 %
Allodynia	2	1.6 %
Restless legs	2	1.6 %
Difficulties in walking and balance	2	1.6 %
Sleep difficulties	2	1.6 %
Disturbances in vision and hearing	2	1.6 %
Nausea without vomiting	2	1.6 %

Abscess at the site of vaccination	1	0.8 %
Erysipelas at the site of vaccination	1	0.8 %
Eye pain	1	0.8 %
Sleep paralysis	1	0.8 %
Unintentionally falling asleep	1	0.8 %
Wide-ranging brain stroke	1	0.8 %
Unconsciousness and absences seizures	1	0.8 %

6. The current symptom picture

At the time when filling the questionnaire the respondents had still various symptoms, which often affected their whole body such as symptoms affecting mobility, muscles, autonomic nervous function, metabolism, thermoregulation, pain, cataplexy, sleeping and sensitivity to infections.

Stiffness of the legs, ankles and feet, muscle pain, inflammation of muscle attachment points and writing difficulties were mentioned as the most debilitating symptoms affecting walking and balance. Over 70% of respondents reported that their fatigue and other symptoms increased after physical stress. Almost 30% of respondents experienced limb muscle weakness. Weakness of the upper limbs was more common than that of lower limbs. Symptoms (thought to be) associated with autonomic nervous system and circulation included dizziness, difficulties in speaking and seeing, tremor, faster heart rate and over excitability. Over 30 % suffered from hypersensitivity to a heartbeat. Almost 30% of the respondents suffered also from orthostatic intolerance.

Signs indicating disturbed metabolism and thermoregulation (e.g. increased or decreased appetite, nausea, problems in weight and glycemic control, need for frequent urination, sweating, feeling of coldness) were still present in some respondents. The other persisting symptoms were pain, sleep disorders and sensitivity to infections. Almost 50 % of the respondents did still experience joint or muscle pain. Stomach ache, nausea and gastrointestinal disturbances were also common.

The persisting psychiatric and cognitive symptoms included fears, mood swings, difficulties in attention and concentration as well as in learning. Mild and severe mood swings occurred in 42 % and 24 % of respondents, respectively, Over 60 % and over 50% of the affected persons suffered from cognitive impairments and brain fog, respectively. The difficulty of speech occurred in over 20 % of respondents.

Table 8 presents the typical symptoms of the respondents at the time when they answered the questions of the survey. Some had been ill for 8.5 years and typically the course of the symptoms had varied significantly; the old already vanished symptoms had returned. The symptoms had disappeared partially or completely only from a small part of respondents after the adequate medication had been found.

Table 8. Current symptoms

Symptom	number	percentage
Tiredness, abnormal need for sleep	112	86.8 %
Increased fatigue or other symptom after physical activity	96	74.4 %
Memory and cognitive difficulties	87	67.4 %
Sleep disorders, catnap dream, recurrent nightmares	84	64.1 %
Difficulty sleeping	79	61.2 %
Brain fog	74	57.3 %
Arthritis	60	46.5 %
Muscle pain	59	45.7 %
Involuntary sleeping	58	45.0 %
Slight mood swings	54	42.0 %
Cataplexy	53	41.1 %
Stomach ache	52	40.3 %
Abdominal disturbances; constipation/diarrhea	53	41.0 %
Sleep paralysis	49	38.0 %
Nausea without vomiting	49	38.0 %
Sensory hypersensitivity vision and hearing	45	34.9 %
Heart rhythm disorders, tachycardia	44	33.3 %
Headache pains, mild	38	29.5 %
Orthostatic intolerance /increased symptoms in upright position	37	28.7 %
Malfunction of the upper limbs, muscular weakness	37	28.7 %
Backaches	34	26.3 %
Muscular weakness of the lower limbs, muscular weakness	33	26.0 %
Severe mood swings, aggressions	31	24.3 %
Irritated bowel	31	24.3 %
Eyes symptoms; eyelid paralysis, diplopia, blurred vision	30	23.6 %
Restless legs	29	22.5 %
Twilight feelings	29	22.5 %
Difficulties in speech, loss of speech	28	21.7 %
Hallucinations	27	21.0 %
Walking difficulties due to pains	27	21.0 %
Automatic functionality	26	20.6 %
Feeling down, depression	26	20.2 %
Continuous fever	25	19.4 %
Severe headache pains	25	19.4 %
Short-lasting absence seizures	24	18.6 %
Eye pains	23	17.8 %
Low blood pressure	23	17.8 %
Migraine	22	17.1 %
Walking difficulties, due to disturbed balance and coordination	22	17.1 %
Obsessive symptoms	17	13.2 %
Allodynia	17	13.2 %
Swallowing difficulties	17	13.2 %

Non-epileptic seizures and twitches	16	12.4 %
Severe allergic reactions	15	11.6 %
Nausea, vomiting	14	10.9 %
Walking difficulties due to spasticity	12	9.3 %
Loss of consciousness, fainting	12	9.3 %
Tic-symptoms	9	7.0 %
Arthritis; heat, flushing, swelling	9	7.0 %
Worsening of previous allergy symptoms	8	6.2 %
Long-lasting absence seizures	8	6.2 %
Disturbances in thermoregulation	5	4.0 %
Periodic spastic seizures affecting limbs and body	4	3.1 %
Epileptic seizures	3	2.3 %
Sensitivity to infections, chronic infections	3	2.3 %
Diabetes	2	1.6 %
Sweating of feet	2	1.6 %
Unexplainable rash	2	1.6 %
Red, hot transient spots in the legs	2	1.6 %
Difficulty in controlling the appetite, weight gain	2	1.6 %
Limb tremor	2	1.6 %
Diminished sexual desire	1	0.8 %

Some of the respondents have described their symptoms after the correct diagnosis and adequate treatment e.g. as follows:

- *“No symptoms, after iv immunoglobulin (IVIG)”*
- *“The most severe symptoms have diminished along IVIG-treatment.”*
- *Symptoms have relieved along biological drug for rheumatoid arthritis”*

7. Performance

As a result of vaccine, there was variation in the physical, cognitive and psychological and social survival of those affected. Table 9 shows the respondents' degree of performance. In addition to replying to a multiple-choice question the respondents were able to describe their performance capability with their own words. Daily actions were managed independently, in part, or in aid. Medication and nap helped in the independent management of daily activities. Some of the affected needed help and aids to manage daily actions. Help was needed especially in those cases in which the affected are almost or completely bedridden. The respondents were able to eat independently, but they could need help in preparation of meals and shopping of goods. Washing and dressing succeeded independently, but accessories, such as shower boxes, were needed for showering.

The motility capability was variable among respondents. Some of the affected needed a wheel chair, in some cases the motility capability was limited and some were able to walk without aids. The aids mentioned in the questionnaire were a car and a wheelchair. The walking capability may have deteriorated and it varied. The affected were not necessarily able to walk long distances.

Muscle strengths, sustainability and sustained condition may be weakened. The affected had difficulties to cope with heavier physical tasks. The physical performance was influenced by difficulties in keeping balance as well as by problems in seeing and hearing.

The cognitive and psychic performance. The affected may have problems in remembering, learning, in data processing, in action control and in concentration. The memory functions may have weakened. Some needed aids and some needed the other person to remind them. Notes, lists, alarm clocks and phone remind were used as a memory support. Consequently, children and adults may suffer from difficulties at school and work, respectively. For instance because of difficulties in data processing, the affected might need assistance when they function with officials and physicians. They may need help from others when filling the requested forms. They may face problems also in verbal functioning, like when producing speech.

The social performance varied among the affected. Several respondents were found to have no energy to continue social relations and thus they had become isolated from the outer world. Some affected were barely able to leave their house. They may leave their house only when they need to go to doctor's appointment. The affected adults had problems in participating their own kids' activities like playing or in taking part in their hobbies. Also the other factors like weak financial situation and lack of society's support may have had a negative impact on social performance. Some respondents brought up that they were able to function almost or completely independently on the right medication. Majority, however, did consider their symptoms so restrictive and diagnoses so obscure that no one has been able to find the effective treatment.

Table 9 summarizes the performing capacity of the respondents.

Table 9. Performance

	number	percentage
I can live independently, but I do need help from others	66	51.6 %
I can live independently without help from others or aid	23	18.0 %
I need frequently assistant's help, but I am not bedridden	18	14.1 %
I need minor help in daily actions; I need aids	10	7.8 %
I am bedridden; I need help in all daily actions	6	4.7 %
I do not need help in daily actions, but I need aids	5	3.9 %

8. Diagnoses

Respondents were diagnosed with different diseases and given various diagnosis codes. On the other hand, some were without any diagnosis in spite of their severe somatic and / or psychic symptoms or their diagnosis was just suspected. The illnesses diagnosed after vaccination included endocrinological (e.g. diabetes), gastrointestinal, neurological (e.g. postural tachycardia syndrome, POTS, G98.9; restless legs, multiple sclerosis, EDS etc.), rheumatoid (incl. several autoimmune diseases some of which possibly hereditary) and psychiatric (e.g. depression, anxiety) diseases. ME/CFS (i.e. Myagic Encephalomyelitis/Chronic fatigue syndrome) was given the following diagnosis numbers R53.3, F48.0 or more commonly G93.3. Table 10 presents the diagnosis

numbers that were given to the diseased persons. In additional individual had received the following diagnoses: ASIA, mitochondrial myopathy, Tourette syndrome, Asperger syndrome, adrenal insufficiency, Stiff person syndrome, Hypersomnia causing disorder, Raynard’s syndrome, panic disorder, parasomnia, sympaticotony, Sella’s microadenoma, childhood anxiety and fear disorder, hypermobility syndrome, wide-ranging post-vaccination brain stroke, hemiplegia, difficulties in speaking, aphasia, autism, CRPS, PANS (suspected), joint and skin psoriasis.

Table 10. Post-vaccination diagnoses

Diagnosis	number	percentage
Narkolepsy	52	40.6 %
ME/CFS (G93.3)	46	36.7 %
POTS (Postural Orthostatic Tachycardia Syndrome)	31	24.2 %
Asthma and other pulmonary diseases	22	17.2 %
Migraine or some other headache	19	14.8 %
IBS (Irritable Bowel Syndrome)	17	13.3 %
HDS/EDS/Unspecified connective tissue disorders	13	10.2 %
Cataplexy	12	9.4 %
Fibromyalgia	12	9.4 %
Thyroid diseases	12	9.4 %
MCS/Multiple Chemical Sensitivity	12	9.4 %
Other brain disease, PANS	6	4.7 %
OCD (Obsessive Convulsive Disorder)	6	4.7 %
Periodic limb movement disorder	6	4.7 %
Dysautonomy	8	6.25 %
Moderate depression	6	4.7 %
Epilepsy	4	3.1 %
Sleep apnea	4	5.2 %
Conversion /Dissociative disorder	4	3.1 %
Severe somatic symptoms, no diagnosis	4	5.2 %
Hypersomnia	3	2.3 %
Anxiety disorder	3	2.3%
Diabetes	3	2.3 %
Juvenile arthritis	2	1.6 %
Rheumatism or the like	2	1.6 %
Neurasthenia	2	1.6 %
Restless legs	2	1.6 %
Reactive arthritis	2	1.6 %
Allergies	2	1.6 %
Scoliosis	2	1.6 %
Atopy	2	1.6 %
Iron deficiency anemia	2	1.6 %

9. Subsistence

Many diseased persons and their families have had difficulties with their subsistence (table 14) due to lost ability to work, capability to do only a part time job or forced need to stay at home for caregiving.

Table 14. Do you have problems with subsistence because of your illness? (123 responses)

	number	percentage
Yes	83	67.5 %
No	42	34.1 %

10. Health care activities toward patients experiencing post-vaccination symptoms

The respondents reported several shortcomings in the public health care services. Diagnosis may have been delayed over two years even though in most persons the symptoms had started within two years. Because of this it may have become impossible to get social support. Apart from delayed diagnostics the respondents have had difficulties in receiving appropriate medical certificates of their health, which has complicated further the application process to obtain social support. Some but not all physicians had been willing to revise their opinion paper in order to help the patients to get social support. Also the speed at which the respondents had received their medical certificates has influenced their chances to get financial support from the state.

The diseased persons may have had difficulties to get treatment like medication. Financial difficulties may have prevented the access to the appropriate treatments, because financial support has not been granted to the treatments offered by private clinics. In addition the physicians working at public hospitals may have refused to renew the prescriptions of private doctors, and public hospitals may have denied the patients access to public treatments.

11. The reports of vaccine adverse reactions

Reporting of a suspected adverse reaction to health officials was considered in general laborious. Over half of the respondents (55%) had reported the suspected adverse reaction. Some of the respondents had reported suspected adverse reactions from several vaccines, e.g. from Pandemrix and HPV-vaccine. Seven of HPV-vaccinated respondents had done adverse reaction notification. One respondent had reported suspected adverse reaction from five vaccines. Some of the respondents did not know what the adverse reaction notification is or was not sure if it had been done or not.

Table 15. Has the suspected adverse reaction been reported to the health officials?

	number	percentage
Yes	71	55 %
No	58	45 %

Table 16. Who did the adverse reaction notification? (74 responses)

	number	percentage
Yourself or your relative	50	67.6 %
Physician	28	37.8 %
Nurse	12	16.2 %

12. Final remarks

There is clearly an urgent need for further studies on vaccine safety. We Finnish parents do wish that this freeform work would burst genuine collaboration between all parties so that adequate scientific investigations would be initiated without any further delays. We consider it also of utmost importance that the medical professionals will be educated to recognize the possible adverse reactions and to report their observations to the health officials.

13. References

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