

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

VACCINATION AND SERIOUS AUTOIMMUNE SYMPTOMS

Introduction

This report is based on an internet-based questionnaire (Attachment 1) 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.

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1. 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. County or 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 % |

2. 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 % |

3. 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.

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

| Rokote | number | percentage |
|-----------------------|--------|------------|
| Pandemrix | 104 | 80.6 % |
| Pandemrix + Influvac | 1 | 0.8 % |
| Pandemrix + Twinrix | 3 | 2.3 % |
| Pandemrix + Cervarix | 9 | 7.0 % |
| Pandemrix + MPR | 3 | 2.3 % |
| 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 % |

Eikö Gardasil'n jälkeen kukaan sairastunut?

4. The outbreak of the disease

i. 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 % |

ii. 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 % |

5. 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 % |

6. 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 was 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.