Coping with narcolepsy after Pandemrix® vaccination – using the social media

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Abstract

Background: In 2010, a number of newly diagnosed narcolepsy cases among children and adolescents were seen in several European countries as a consequence of comprehensive national vaccination campaigns with Pandemrix® against H1N1 influenza. Since then a large number of people have had to live with the disease and its consequences on daily life such as affected school life, social relationships and activities. Initially the side effects were not well understood and there was uncertainty about whether there would be any financial compensation. The situation remained unresolved until 2016, and during these years affected people sought various ways to join forces to handle the many issues involved, including setting up a social media forum.

Objective: Our aim is to examine how information was shared, and opinions and beliefs about narcolepsy as a consequence of Pandemrix® vaccination were formed by discussions in the social media.

Methods: Series of messages posted in a social media forum for people affected by narcolepsy after vaccination are investigated by quantitative and qualitative methods.

Results: The group activity was high throughout the years 2010–2016, with peaks corresponding to major narcolepsy-related events, such as the appearance of the first cases in 2010, the first compensation paid in 2011, and the law on compensation passed in July 2016. Unusually, the majority (60%) of the group took part in discussions and only 40% were lurkers (compared with the usual 90% according to rule of thumb).

The conversation in the group was largely factual and had a decent tone, even though there was a long struggle to get acknowledgement of the link between the vaccine and narcolepsy and regarding the compensation issue. Radical, non-scientific views, such as those expounded by the anti-vaccination movement, did not shape the discussions in the group but were active elsewhere on the Internet. At the outset of the pandemic, there were 18 active Swedish discussion groups on the topic, but most dissolved quickly and only one Facebook group remained active throughout the period.

Conclusions: The group studied is a good example of social media use for self-help through a difficult situation among people affected by illness and disease. This shows that social media do not by themselves induce trench warfare, but, given a good group composition, can
provide a necessary forum for managing an emergency where health care and government have failed or are mistrusted, and patients have to organize themselves so as to cope.

**Key words:** narcolepsy, mass vaccination, social media
**Introduction**

In 2010, a number of newly diagnosed narcolepsy cases among children and adolescents was reported in several European countries, as a consequence of comprehensive national vaccination campaigns with Pandemrix® against H1N1 influenza (swine flu) that took place during the winter of 2009–2010 [1]. In Sweden, approximately 350 young persons acquired narcolepsy after vaccination against swine flu [2, 3]. Narcolepsy is a neurological disease that involves a disturbed regulation of wakefulness and sleep. The main symptoms are severe insomnia and daytime sleep attacks that cannot be controlled. Cataplexy, a sudden loss of muscle tone and a feeling of paralysis, is commonly associated with narcolepsy and can have a significant impact on the daily lives of the affected persons. There is no curative treatment, only symptom relief with stimulant drugs, antidepressants and sodium oxybate (Xyrem®), which all have fairly tough side effects [4].

Despite a lack of scientific documentation of the life situation of young persons who acquired narcolepsy after swine flu vaccination, several personal descriptions have been published in the media (newspapers and the Internet) and aired on TV. Having grown up in the digital age, young people are today accustomed to expressing their opinions quickly and widely using the social media. In a crisis, social media could potentially be a significant means for disseminating and collecting information and could serve to improve emergency management, for example. On the other hand, the social media have been ascribed the power to misinform [5]. Social media are described as an amplifier of opinions more than as an arena for objective discussions [6-8] and the health information presented is often inaccurate and/or not in line with official recommendations for prevention and treatment. For many people, attitudes towards vaccination are shaped not just by health care but also by other information sources published on websites and in social media. In the case of vaccination campaigns, several anti-vaccine movements opposed to, for example, vaccination against human papilloma virus (HPV) and measles have been started through social media [9, 10]. The relation between narcolepsy and the swine flu vaccination campaign is often used in blogs as an example of why the medical authorities should not be trusted [11].

As social media and the Internet are seen by many as a primary source of health-related information [12, 13] and can change how young people share information and make decisions regarding their health and wellbeing, it is important to investigate how information,
perceptions and attitudes are spread. The power of social media puts new demands on communication strategies of health care systems.

Our aim is to examine how information is spread, and opinions and beliefs about narcolepsy as a consequence of Pandemrix® vaccination are formed by discussions in the social media. For this purpose, we examined series of messages posted on social media as well as connections among people participating in the discussions. Our hypothesis was that, in general, social media groups for persons actually affected by narcolepsy are factual and constructive and help narcolepsy sufferers to cope with the situation, and that the negative campaigning against vaccination comes from other sources. If this was confirmed, it would mean that social media are not the main driver of unfactual discussions; rather, group composition is.

This study is part of a project investigating the life situations of narcolepsy-affected young persons, and the use and meaning of social media and the Internet as a means of support and communication of opinions [2]. It is hoped that the results of the study will increase knowledge of how the use of social media can affect trust in health care and attitudes towards future health campaigns, and thereby assist in developing interventions to support increased trust in and compliance with such campaigns.

Background: Swine flu outbreak and vaccination in Sweden

The swine flu virus was first isolated from pigs in 1931. The first known death of a human due to the virus was described in 1976. In 2009, a new type of swine flu virus emerged in California, which was quite harmless to most people, while some individuals who did not belong to traditional risk groups became extremely ill. Within a few months, the flu became pandemic and many countries decided to offer their citizens a pandemic vaccine campaign [1]. In connection to the 2009/2010 pandemic, about 60% of Sweden’s population were vaccinated against swine flu [14, 15]. In 2010 came the first reports from Finland and Sweden of narcolepsy among children and adolescents vaccinated with one of the vaccination types, Pandemrix®. Since then, studies from Sweden, Finland, the UK and Ireland have demonstrated a link between narcolepsy and the Pandemrix® vaccine, with the latter producing a threefold increase in the risk of narcolepsy [1]. When the link between the vaccination and narcolepsy was clarified, claims were made among the families of the affected children, and later also by the adolescents themselves, for compensation from
pharmaceutical companies, medical insurers, the health authorities and others. In Sweden, health care including disease prevention is regulated and performed by the public sector; consequently, the government was the main target for these demands. Among other things, discussions revolved around the maximum limit of compensation. Table 1 lists the most significant events during the period from March 2009, when the virus was detected, until July 2016, when the dispute in Sweden was settled by legislation regulating compensation to affected individuals. Different actions to call for higher compensation were initiated, using channels such as newspapers, TV and the Internet.

Table 1. Significant events concerning the swine flu outbreak, vaccination, narcolepsy and compensation regulation.

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>March 2009</td>
<td>Reports emerge of a new type of swine flu in California and Texas and spreading to Mexico</td>
</tr>
<tr>
<td>June 2009</td>
<td>WHO declares swine flu pandemic. Vaccine development begins</td>
</tr>
<tr>
<td>October 2009</td>
<td>The Swedish vaccination campaign starts</td>
</tr>
<tr>
<td>August 2010</td>
<td>Reports of narcolepsy in vaccinated children emerge from Finland and Sweden</td>
</tr>
<tr>
<td>July 2011</td>
<td>The EMA recommends limited use of Pandemrix® in people under the age of 20</td>
</tr>
<tr>
<td>October 2011</td>
<td>The first persons who had narcolepsy after vaccination receive compensation from the Swedish pharmaceutical insurance</td>
</tr>
<tr>
<td>March 2013</td>
<td>The first register study is published, showing the link between Pandemrix® and narcolepsy, as also exposed in the daily media</td>
</tr>
<tr>
<td>May 2015</td>
<td>The Swedish government sets the maximum compensation amount for lost income at 10 million SEK</td>
</tr>
<tr>
<td>July 2016</td>
<td>A new law is passed regarding compensation from the Swedish pharmaceutical insurance to affected persons who experienced the first symptoms of narcolepsy &lt;24 months after the vaccination</td>
</tr>
</tbody>
</table>

EMA = European Medicines Agency; WHO = World Health Organization.

Methods

This study is a descriptive retrospective analysis of a series of messages posted on social media, as well as connections between users, between September 2010 and July 2016. The study was conducted in 2017. We found 18 Swedish discussion forums on the web that
concerned narcolepsy and that had started around 2010. In most of these, the volume of
activity was very low, with only a few posts. Most of the forums also had no posts from recent
years: the narcolepsy vaccination took place in 2010, the first cases of narcolepsy occurred the
same year, and most posts in these groups were from around that time. We selected the only
group that had a large number of posts and where activity has been high throughout the years.
This is a Facebook group in Sweden named “Narcolepsy after the Pandemrix Vaccine” (hereafter referred to as “the group”)
(https://www.facebook.com/groups/122068704510686/about/), which had 774 members as of
12 September 2016. The group is presented as “a group for us, or relatives, who have the
diagnosis of narcolepsy or have similar symptoms like narcolepsy/sleeping sickness after
vaccination”. Although the group is open, it is reasonable to assume that most people in the
group are in fact either affected or close relatives of those affected by the disorder. When the
group started, a total of 200 people were affected by, that is, had been diagnosed with,
narcolepsy after vaccination. Add to those a few who had the symptoms but had not yet been
diagnosed, and between two and three relatives per affected person, and a total of around 774
is reached. This suggests the group is in fact (voluntarily) limited to narcolepsy patients and
their close relatives. The group has been active since September 2010, and at the time of our
investigation there had been a total of 1,671 posts which had generated altogether 10,906
comments.

Data collection
Some data were collected directly from the group, such as count of posts (a “post” is the start
of a discussion on Facebook) and comments. For the content analysis, we selected posts with
more than ten comments from months with high activity, defined as ≥200 posts or
comments/month. This selection criterion yielded 141 posts out of the total of 1,671 that were
available at the time. The reason for this selection was that we wanted to see what discussions
that “caught on” were about. Postings that generated many comments can be considered more
interesting to the group than those that do not. While the limit of ten comments is somewhat
arbitrary, it serves to sort out posts that only receive marginal comments (e.g. “good to hear
from you”), corrections (e.g. “sorry, 25 is the correct number”) or clarifications (e.g. “Where
did you hear that?” – “In…”; “But they made an update this morning saying […]”). The
selection includes 8.4% of the total number of posts and 28.3% of the comments. The
remaining 1,530 posts (that we did not select) had an average of five comments.

Text data were downloaded from the group using Netviz v 1.31
to identify postings with more than ten comments. The software program NVivo 11 for Mac (QSR International, Doncaster, Australia) was used for quantification of data, i.e. analysing numbers of postings and users.

**Data analysis**

Text data were sorted by the third author into postings and comments regarding users. An inductive approach was used, which involved reading the data and identifying headings describing the content of the postings and comments. The analysis was conducted in several iterations involving all authors, and including discussion of interpretations of what was said in posts and comments, and various alternatives for quantifying the results, for example by author, key words, frequency, and more. The analysis process was driven by a set of analytical questions regarding content, participation, and communication style:

1. **Content**
   a. What are the most common discussion topics?
   b. How do discussion topics change over time?
   c. What triggers the major discussions (e.g. external events like news media stories or government/health care system actions, or internal events such as somebody working to raise awareness or personal experiences shared)?

2. **Participation**
   a. How many people/how large a share of group members participate in discussions?
   b. How many start discussions?

3. **Communication style**

**Ethical considerations**

As previously mentioned, the group is open and all postings and comments, as well as the names or pseudonyms of the people who have written them, are publicly visible. No individual’s posting or commenting in the group can be identified in this research, either by group member name or by the content of their postings. We handled data in line with the Declaration of Helsinki (https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/). According to Swedish law, studies on social media do not require ethical approval; however, the overall project has gained approval from the Regional Ethical Review Board of Uppsala (reg. No. 2013/505).
Results

Content

The group activity was fairly high throughout the years 2010–2016, although there was considerable monthly variation (Figure 1). The peaks of the activity correspond with the major events over the years, that is, the first cases of narcolepsy in late 2010, the first compensation paid in late 2011, and the law on compensation in July 2016 (see Table 1). But there is also sustained high activity from late 2012 to early 2014. While no milestone event took place during that period, it was a time when new cases of narcolepsy were being discovered and many more people found themselves struggling with a difficult situation.

![Posts and comments over time](image)

*Figure 1. Group activity during the period September 2010–August 2016.*

The most common discussion topics

The most common discussion topics were:

1. Side effects of Pandemrix®/the vaccination: 37 posts
2. Drugs and medication: 28 posts
3. Narcolepsy diagnosis: 17 posts
4. Insurance and compensation: 16 posts
5. Doctor/hospital visits and treatments: 12 posts
6. Vaccination in general: 8 posts
7. Events/meetings: 8 posts
8. Upset discussions about public statements by an official or journalist: 5* posts
9. Scientific research: 2 posts
10. Other: 8** posts

*This includes statements by radio hosts (n=2), politicians (n=2), and the Head of the Swedish Institute for Infectious Disease Control (n=1).

**These include eight different topics with only one posting each, ranging from Christmas greetings to blood donation to a conspiracy theory about whether the government had known about the side effects.

Changes in discussion topics over time
Discussion topics changed over time (Figures 2–7). Some topics, such as “Drugs and medication” or “Narcolepsy diagnosis” (Figures 3 and 4) were on the agenda more or less all the time, albeit with varying frequency. Peaks correspond to significant narcolepsy events, such as, initially, the increase in cases in 2011–2012, then the corroborated link between the vaccination and the disease in 2013. “Side effects” also remained a hot topic for a long time, peaking in late 2012 and 2013 when the relation to the vaccination was first investigated and later established (Figure 4). Other themes, like “Insurance and compensation” and “Doctor/hospital visits and treatments” (Figures 6 and 7), emerged frequently for shorter periods, following significant events after the vaccination campaign had started in 2010 (see Table 1). “Doctor/hospital visits” was a frequent topic during 2011–2012 when the pandemic exploded. It was followed by another, smaller peak in May 2013, which coincides with, and could be related to, increased publicity at the time about the link between Pandemrix® and narcolepsy, based on the first Swedish register study [14, 15] published on the website of the Swedish Medical Products Agency in 2013, and exposed in the daily media. The topic was then related to the importance of having a diagnosis in order to qualify for compensation. The topic “Narcolepsy diagnosis” was a frequent discussion topic from 2013, when the cause was established and discussions on compensation became active in the media, until 2016 when the new law settled the compensation issue. “Insurance” was another major topic in late 2013, when the first study established the link between Pandemrix® and narcolepsy, which naturally triggered discussion about compensation.

Even the more constant topics had ups and downs over the investigated period. For example, discussions of the “Side effects of Pandemrix®” were frequent throughout the period but there was a major peak during the period from February 2012 to January 2013, coinciding with the media discussion during that period.
Figure 2. Posting topics with high activity.

Figure 3. Postings on drugs and medication.
Figure 4. Postings about narcolepsy diagnosis and the side effects of Pandemrix®.

Figure 5. Postings about narcolepsy diagnosis.
Discussion triggers

While peaks in discussion topics can be related to significant events in the history of the vaccination and ensuing pandemic, there is still the question of which events, situations, needs, or emotions trigger specific major discussions. As Table 2 shows, the by far most common cause prompting the writing of posts was personal need for finding and sharing information. Only a small number of posts (n=8) contained “negative discussions”. These
were reactions to public statements by officials or journalists, which were felt to be derogatory. Only one post aired a conspiracy theory, and this did not take root.

Table 2. Rationale behind the posts.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number of Posts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Searching for information/others’ experience</td>
<td>46</td>
</tr>
<tr>
<td>Sharing personal experience/information</td>
<td>44</td>
</tr>
<tr>
<td>Sharing information from external sites</td>
<td>27</td>
</tr>
<tr>
<td>Sharing information about an upcoming event/meeting</td>
<td>8</td>
</tr>
<tr>
<td>Airing statements by the media</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
</tr>
<tr>
<td>Presenting a conspiracy theory</td>
<td>1</td>
</tr>
</tbody>
</table>

(Total: 141)

The general tone of the discussions was factual, friendly and positive despite the problematic, to say the least, situation many of the group members found themselves in. They tried to share information and experiences with each other in the hope of easing the life of “the victims”. The posts were generally by a member seeking answers and experiences from the other members of the group, or someone wanting to share information or personal experiences with the group.

There were only 13 posts (9%) of a more negative character, and even in these threads the tone was mainly factual. When the members expressed anger in their posts it was anger they felt either towards individuals (politicians, officials, or a media host) who made statements about the situation, which group members felt were unfair or derogatory (n=4), or towards individuals who had purportedly exploited the situation to commit insurance fraud (n=1), or it was to express dissatisfaction with a doctor (n=2) or anger towards the Head of the Swedish Public Health Agency (n=1). Alternatively, it was about insurance and compensation (n=2), about incorrect information on a website (n=1), or demands for a public apology from the government (n=1). In one case a conspiracy theory claiming that the government had known about the side effects beforehand was published.
Participation

The group had 774 members by the time of our investigation. Over the lifetime, by then, of the group there had been a total of 1,671 published posts, with 10,906 comments. We selected the “major” discussions, those which generated ten or more comments.

In all, 59.7% (n=462) of the group members had participated in the discussions by either creating or commenting on a post. Slightly more than one-third of the group members, 35.8% (n=277), had created a post (that is, started a discussion).

The five people who contributed the largest number of discussions account for 26.0% (n=435) of the posts published in the group. They also provided 22.2% (n=2,423) of all the comments on the forum.

The ten people (1.2% of the population) who created the largest number of discussions account for 42.2% (n=705) of the posts that generated most comments. They also provided 35.2% (n=3,838) of all comments on the forum. The single most active member had created 107 posts – 6.3% of the total number of posts. Seven members had created ≥50 posts each.

Thirty-two members had created more than ten posts in the group. All the other 445 active posters had provided an average of 1.7 posts.

These numbers are considerably higher in terms of participation than the general rule of thumb for social media use. The “99–9–1% rule” (Nielsen, 2006 #232) states that in most online communities, 1% of users account for almost all the action, 9% of users contribute a little, and 90% of users are lurkers who never contribute. In the community we analysed, we found agreement on the first statement of the “rule” but not the second or third. In this population 1.2% of participants accounted for 42% of the posts and 35% of the comments.

While not statistically constituting the majority, this is certainly a major part. We also found that the majority of members of the community – 59% if we take away the most active 1% – contributed at least something. The share of lurkers, if defined as people who never actively participate, in our study was then only 40%. Even though many only had made one or a very few posts, posting means starting, or trying to start, a discussion, which can be considered more active participation than commenting on someone else’s post.

Generally speaking, the group we studied, then, can be considered fairly participatory by general social media standards, even though a few people clearly dominated the discussions.
Presumably this means that not only was the group considered highly relevant to the participants; active participation was also important, and the group was trusted enough for many people to share even sensitive stories from their lives.

**Discussion**

The aim of this study was to examine how information was disseminated, and how opinions and beliefs about narcolepsy as a consequence of Pandemrix® vaccination were formed by discussions in the social media. To investigate this, we examined series of messages posted on social media over a 6-year period. The focus was on people affected by narcolepsy after having been vaccinated against swine flu. Out of 18 Swedish groups originally discussing this topic, the Facebook group we examined was the only one that has remained active throughout the years.

Our hypothesis, that social media groups for affected patients are generally factual and constructive and help the patients cope with the situation, and, further, that negative campaigning against vaccination comes from other sources, was motivated by a more general research interest, namely that the social media do not inherently drive unfactual discussions and/or less honest discussion styles. Rather, that the social media are a useful tool not just for social purposes but also for really difficult discussion on very serious matters that concern people’s health. If the hypothesis holds, then social media can be very useful not just for the people participating but also for health care providers. Interventions using social media, i.e. Facebook, in health care are increasing, for example including interventions for: awareness of breast cancer [16], physical activity promotion among adolescent and young adult childhood cancer survivors [17, 18], sexual health promotion [19], HIV communication [20], and enhancement of positive health outcomes among adolescent and young adults [21]: all studies referenced here indicate positive benefits. However, there is still a lack of robust evidence of effects and concerning how to best design such interventions. Despite an increased use of social media by health care providers, issues remain how to best provide health information and support that are trustful, and that promote healthy behaviour among people. The group studied here was self-organized, and this may have been a factor affecting people’s trust in it.

If social media themselves do not drive unfactualism and asocial behaviour, then certainly people and group composition might. This particular group was composed of people who
shared the same, serious, situation and great need, not just for information, but for advice and the possibility to share their concerns with others. It should be noted, however, that most of them did not know each other in “real life”. They lived in different cities and were dispersed across Sweden. In this respect theirs was a truly virtual community. From previous research on social media we know that distance makes social ties weaker. Harsh language is more common when people live far apart from each other than when they live in the same city and there is at least a theoretical chance that they might physically meet. It appears that in the case we studied, the shared situation served the purpose of making people feel close enough to make the community “real”.

This type of scenario creates opportunities for health care, as many patients with some serious condition share the same situation: they need to learn about their problem and possible treatments and they have to cope with their situation. They often do not know people with the same condition at the outset but want to find them as the need arises. Whatever the condition, in most cases most people with the same condition do not live next door. Regarding the sharing and disclosing of experiences of illness and health, some people prefer to do this in forums like Facebook, while others are hindered by the lack of anonymity in social media [22]. The resource here presented might also be limited to people with Internet skills and access, and may exclude people from socially disadvantaged groups with lower socioeconomic status [23].

Of course, one case does not prove a hypothesis, but at least this case gives positive evidence of the possibilities that social media can present to these people living with an uncommon but serious condition in a difficult and uncertain situation. Despite several years having passed since the onset of the first vaccination-related cases of narcolepsy, this Facebook group still exists. This could indicate a need for support – support from society and, even more importantly, from health care.

Although the discussions in the group were generally factual, positive and directed towards problem solving and coping, rather than bitterness and conflict, we did find one post putting forward a conspiracy theory. While there may have been more negativity in the posts with fewer than ten comments, these did not lead to any longer discussion. Much has been written about how social media amplifies opinions [6-8], but it has also been found that conflict in discussion forums often occurs between groups rather than within them. For example, at “hate sites”, traditional media are criticized while criticism against hate sites mainly occurs at
traditional media sites. The same seems to be the case here. There was little conflict in this group, either internally or externally (for example, through members attacking people outside the group), but it is easy to find other places on the web where anti-vaccination views are vigorously and often aggressively expressed.

It would be interesting to investigate why some postings do not generate comments – is it because they are inappropriate, marginal, or made by people who are not centrally positioned in the group? The present investigation, however, is not about the social situation of the group per se, but about the general role of a group such as this, regarding discussions about a severe disorder.

**Conclusion and implications**

The aim of this study was to examine how information was shared, and opinions and beliefs about narcolepsy as a consequence of Pandemrix® vaccination were formed by discussions in the social media. To investigate this, we examined series of messages posted on social media over a 6-year period. We found –

- High group activity throughout the years 2010–2016, with peaks corresponding in time with major narcolepsy-related events, such as appearance of the first cases in 2010, the first compensation paid in late 2011, and the law on compensation in July 2016.
- Unusually, a majority, 60%, of the group members took part in discussions and only 40% were lurkers (in contradiction of the 99-9-1% rule of thumb).
- The conversation in the group was largely factual and had a decent tone, even though there was a long period of struggle to get acknowledgement of the link between the vaccine and the disease and regarding the compensation issue.
- Radical, non-scientific views, such as those of the anti-vaccination movement, did not shape the discussions in the group but were active elsewhere on the Internet. At the outset of the pandemic, there were 18 active Facebook groups on the topic, some very critical and loud, but most faded quickly and only this group was active throughout the period.

The group studied is a good example of social media use for patient self-help in a difficult situation. The example shows that social media do not by themselves induce trench warfare but – given a good group composition – can provide a necessary forum for managing an
emergency where health care and government have failed and are mistrusted and patients have to organize themselves so as to cope.

The critical factor is not social media use, but group composition. The group studied here appears to have consisted only of people directly concerned – individuals directly affected and their close families, and, furthermore, people who appeared to believe in facts and science, even though the pandemic started by a health care mistake. This socially coherent and fact-oriented discussion group survived 6 years, while 17 other groups, many of which included much more confrontational language and views, that appeared at the outset of the crisis soon faded away.

This means that trust in government and health care is very important for the outcome of social media discussions. It must be strong enough to survive even tough challenges, such as this 6 year-long struggle. This trust cannot exist only beforehand but must be reinforced during the process.

Disclosure
None of the authors has any conflict of interest to disclose.

References