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## Covid-19 vaccine hesitancy

### A mixed methods investigation of matters of life and death

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## COVID-19 VACCINE HESITANCY: A MIXED METHODS INVESTIGATION OF MATTERS OF LIFE AND DEATH

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### ABSTRACT

In this article, hesitancy towards COVID-19 vaccinations is investigated as a phenomenon touching upon existential questions. We argue that it encompasses ideas of illness and health, and also of dying and fear of suffering. Building on a specific strand within anti-vaccination studies, we conjecture that vaccine hesitancy is, to some extent, reasonable, and that this scepticism should be studied with compassion. Through a mixed methods approach, vaccine hesitancy, as it is being expressed in a Swedish digital open forum, is investigated and understood as, on the one hand, a perceived need of protecting one's body from techno-scientific experiments, and thus the risk of becoming a victim of medicine itself. On the other hand, the community members express what we call a tacit belief in modern medicine by demonstrating their own "expert" pandemic knowledge. The analysis also shows how the COVID-19 pandemic triggers memories of another pandemic, namely the swine flu in 2009–2010, and what we term a medical crisis that occurred then, due to a vaccine that caused a rare but severe side effect in Sweden and elsewhere.

Keywords: COVID-19; pandemic; vaccine hesitancy; mixed methods; topic modelling; illness narrative; social media, Flashback Forum

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## 1 INTRODUCTION

During the COVID-19 pandemic we witnessed heated, polarised debates over vaccination in society. In many countries, the majority, who were vaccinated,<sup>1</sup> have had difficulty understanding their fellow citizens' reluctance to take this evidently effective measure (Watson et al. 2022), accusing “them” of lacking feelings of solidarity towards others in need of disease protection. In this article, we will investigate and clarify this dissensus based on a study of digital conversations dedicated to COVID-19 vaccines in a Swedish context, with a special interest in vaccine hesitancy.<sup>2</sup> In March 2023, more than 670 million people in the world have been infected with the corona virus SARS-CoV-2, and close to 7 million have died.<sup>3</sup> Billions went into lockdowns during 2020 and 2021. Some countries, such as Sweden, remained open. Nevertheless, people by and large conformed to official social-distancing recommendations. These were a governmental safety measure intended to stop the spread of the virus, which, likely, led to citizens increasingly using the internet to communicate their beliefs, feelings, opinions and information about the pandemic restrictions and measures.<sup>4</sup>

A growing body of research concerning the influence of social media on COVID-19 vaccine information spreading is currently emerging. In a cross-sectional systematic review by Cascini et al. (2022), 156 international articles are identified which reported outcomes related to COVID-19 vaccine attitudes and social media use. Among these, studies that performed thematic analyses of extracted social media data related to vaccine opinions “demonstrated the potential for polarized views to be amplified using social media [implying that] [u]nderstanding this notion has profound benefits for targeting misinformation and combating false-news preaching ‘bubbles’” (Cascini et al. 2022: 35). Similar to the study by

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<sup>1</sup> Globally, 13 billion doses of COVID-19 vaccines have been administered according to Johns Hopkins University's Corona Virus Resource Center, <https://coronavirus.jhu.edu/map.html> (accessed on 2023-03-14).

<sup>2</sup> The research presented in this article was conducted within the framework of the 4-year project *Rumour Mining* (Riksbankens Jubileumsfond grant # MXM19-1161:1), with the goal to study vaccine hesitancy and vaccine rumours in Swedish social environments.

<sup>3</sup> Johns Hopkins University's Corona Virus Resource Center, <https://coronavirus.jhu.edu/map.html> (accessed on 2023-03-14).

<sup>4</sup> See Internetstiftelsen's [The Internet Foundation] survey from 2020, showing an increase of social media use in Sweden during 2020, <https://svenskarnaochinternet.se/rapporter/svenskarna-och-internet-2020/sociala-medier/fler-anvander-sociala-medier-under-pandemin/#2020-7.1> (accessed on 2023-03-14). For an overview of the social media use increase in other parts of the world during phases of the COVID-19 pandemic, see Rosen et al. (2022).

Cascini et al. (2022), much of the literature about COVID-19 vaccine hesitancy more generally is concerned, implicitly or explicitly, with the task of coming to grips with the problem; that is, it has a normative point of departure. It seeks to understand vaccine-hesitant individuals' unsettling perceptions with the purpose of offering them solutions and, by extension, increasing COVID-19 vaccine uptake. Survey investigations draw conclusions regarding the importance of, e.g., traditional pro-vaccination campaigns (Schmidtke et al. 2022), multimedia vaccine promotions (Frankenthal et al. 2022), improved education for health professionals (de St Maurice et al. 2022), and governmental strategies to convince citizens to take the shot (Lindvall and Rönnerstrand 2022).

We do not question the importance of this research but will aspire to move beyond it by building on a strand within vaccine hesitancy research more broadly which we term *compassionate anti-vaccination studies*. In doing so, we strive to contribute to a nuanced understanding of this phenomenon by assuming that people on opposite sides of the vaccine debate share some fundamental traits. For example, all human beings have bodies that can be both strong and vulnerable, and all human beings get sick and die at some point – circumstances that we may fear but still have to live with. And as vaccines protect us from illness, and eventually also from dying, it is a phenomenon encompassing existential dimensions, we argue, that is, matters of life and death and what it means to be living. This applies as much to people who talk about COVID-19 vaccinations in positive terms as to people who discuss them critically. Like all research, our study is ultimately driven by curiosity, but also by a desire to increase our understanding of the world, on the premise that greater understanding also generally leads to better coping.

Two interrelated intellectual starting points inform our study. First, we claim that vaccine hesitancy is, to some extent, reasonable. Second, we assert that vaccine scepticism should be studied with compassion. Thus, through this non-dismissive approach we aim to understand how COVID-19 vaccine hesitancy is expressed on Sweden's largest open forum on the internet, Flashback Forum, using a research methodology mixing (quantitative) topic modelling with (qualitative) narrative analysis. With close to 1.5 million registered users and 80 million published posts, it is even one of the largest open web forums in the world according to some researchers (Wahlström and Törnberg 2021: 771).<sup>5</sup> Our article addresses the following research questions: What is being said about COVID-19 vaccinations on the forum? And in relation to this, what kind of illness stories are being told through hesitancy towards COVID-19 vaccines? How

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<sup>5</sup> Figures from March 2023, <https://www.flashback.org/> (accessed on 2023-03-14).

is the fear of the side effects of vaccination<sup>6</sup> described and, ultimately, what can we learn about the community members' belief and disbelief in modern medicine by studying these conversations?

The outline of our investigation is as follows: firstly, we introduce the reader to the Swedish pandemic context and the background literature which we have consulted. Secondly, we present our material and methods. After this, the analysis is developed, starting with the topic modelling analysis, which leads the way to an exploration of the illness narrative. We round up the article with our conclusions and suggestions for further research.

## 2 COMPASSIONATE ANTI-VACCINATION STUDIES

Sweden managed the intense phases of the COVID-19 pandemic with high vaccination rates<sup>7</sup> but also a declining satisfaction among the population with the government's pandemic response (Andersson 2021), which differed markedly from that of other countries in Europe. While the neighbouring Nordic countries were closing down Sweden remained relatively open, which gave rise to harsh criticism from pandemic experts and politicians in Norway, Denmark and other parts of the world. Heated media debates about "Sweden's gamble" ensued, engaging both members of the public and medical experts (Vogel 2020; Claeson and Hanson 2021a, 2021b).

According to a national survey from 2021, a minority (4%) of the Swedes stated that they would most likely not take the COVID-19 vaccination, or refuse it altogether, expressing a distrust in the vaccines which seemed to correlate with a lack of trust in the authorities (Rönnerstrand 2021). The same study also shows that as much as one fifth of the Swedish citizens were of the opinion that there is a risk of severe side effects caused by the vaccines. This indicates that the fear of adverse vaccine effects is something that also people willing to take the shot seem to grapple with. One should also note that the COVID-19 pandemic did not occur in a cultural vacuum. In 2019 WHO identified vaccine hesitancy – "the reluctance or refusal to vaccinate despite the availability of vaccines" – as

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<sup>6</sup> It is well-known that the fear of side effects affects people's willingness to vaccinate (Björkman and Sanner 2013).

<sup>7</sup> 86.3% of the Swedish population had taken two doses of vaccination against COVID-19 in February 2023, <https://www.folkhalsomyndigheten.se/folkhalsorapportering-statistik/statistikdatabaser-och-visualisering/vaccinationsstatistik/statistik-for-vaccination-mot-covid-19/> (accessed on 2023-04-04).

one of ten urgent threats against public health.<sup>8</sup> The reason for this was that measles had seen a 30% increase in cases globally. Not all of these cases were due to vaccine reluctance but it is a fact that some countries that were close to eliminating the disease now have to deal with a resurgence.

What we will show through our analysis is that memories from the (A)H1N1 swine flu pandemic come into the picture when Flashback members discuss COVID-19 vaccines. For this reason, we will give a brief overview of the events that occurred at that time. In 2009–2010, the swine flu vaccine Pandemrix (marketed by GlaxoSmithKline), resulted in a serious but rare side effect. Out of 1.5 million Swedish children who were vaccinated, approximately 500 developed narcolepsy, a severe, chronic neurological disease (Nihlén Fahlquist 2018; Lundgren 2015b, 2017).<sup>9</sup> The cases of narcolepsy caused by Pandemrix demonstrate how adverse vaccine effects could still occur despite Sweden's highly efficient pandemic preparedness, and even though more than a decade has passed the story has not come to an end. In February 2023, 479 people filed a collective claim with the Chancellor of Justice directed towards the Swedish state for compensation of 32 million euros.<sup>10</sup> However, lessons have been learnt. As

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<sup>8</sup> <https://www.who.int/news-room/spotlight/ten-threats-to-global-health-in-2019> (accessed on 2023-03-14).

<sup>9</sup> Figures from an e-mail-conversation (2022-04-07) with Anders Hultman, Deputy CEO at Svenska Läkemedelsförsäkringen AB, a national company that handles all pharmaceutical injuries in Sweden, show that 740 reports of narcolepsy have been made, and for about 440 of them the state has assessed that the disease was caused by the Pandemrix vaccine. It is now Kammarkollegiet (Legal, Financial and Administrative Services Agency) that handles incoming injury claims: <https://www.kammarkollegiet.se/vara-tjanster/ersattning-och-inkomstgaranti/ansok-om-statlig-ersattning-for-narkolepsi> (accessed on 2023-03-14). The first to report about this adverse effect was the Finnish physician Markku Partinen (Partinen et al. 2012; Sarkanen et al. 2017). Subsequently, the increase of narcolepsy cases caused by the Pandemrix vaccine has been confirmed by other studies, <https://www.sciencedirect.com/topics/neuroscience/pandemrix> (accessed on 2023-03-14). More about the Pandemrix consequences in Norway can be found here: <https://sciencenorway.no/childrens-health-diseases-sleep/children-who-got-narcolepsy-after-the-swine-flu-vaccine-struggle-with-obesity-and-depression/1784818> (accessed on 2023-03-14). In 2011, The European Medicines Agency (EMA) recommended restricting use of Pandemrix, <https://www.ema.europa.eu/en/news/european-medicines-agency-recommends-restricting-use-pandemrix> (accessed on 2023-03-14). An estimation from 2015 is that 1,300 people in Europe developed Pandemrix caused narcolepsy, <https://www.science.org/content/article/why-pandemic-flu-shot-caused-narcolepsy> (accessed on 2023-03-14). To put this figure into perspective, the vaccine was given to more than 30 million Europeans.

<sup>10</sup> A debate article about the complaints was published in Dagens Nyheter, one of Sweden's largest dailies <https://www.dn.se/debatt/narkolepsidrabbade-kraver-staten-pa-363-miljoner-kronor/> (accessed on 2023-03-14). The claim for damages is based on the

a direct consequence of the swine flu experiences a national vaccination register was established, regulated by law, in order to, among other things, facilitate side effect surveillance.<sup>11</sup> In reference to the Pandemrix induced cases of narcolepsy, the biomedical ethicist Jessica Nihlén Fahlquist writes that the “concerns of lay people should not be seen as signs of ignorance, but as a starting-point for a responsible and respectful discussion” (Nihlén Fahlquist 2018: 187).

It is against this background that we venture to claim that vaccine hesitancy is, at least to some extent, reasonable, which leads to the idea of the importance of a compassionate stance towards people who express anti-vaccination opinions and sentiments. The term was introduced by the anthropologist Elżbieta Drażkiewicz, though it was presented slightly differently in a piece published in *Nature’s World View* section entitled “Study conspiracy theories with compassion”. She writes as follows:

Motivated to end the pandemic, and to encourage vaccination and other health-promoting behaviours, many researchers new to the subject are asking how best to ‘confront’ or ‘fight’ conspiracy theories, and how to characterize people wary of medical technologies. But my field has worked for decades to push back on this tendency to pathologize and ‘other’. Whether researchers are trying to understand beliefs around vaccination or theories surrounding NATO, Russia and bioweapons labs, such framing limits what can be learnt. Conspiracy theories are more about values than about information. Debunking statements might occasionally be effective, but does little to tackle their root cause. (Drażkiewicz 2022: 765)

Drażkiewicz underscores the risks of the “us versus them” framing of the vaccination issue, leading to descriptions of fellow humans as *those people*, “obsessing over characteristics that make them distinct – especially from the researcher” (Drażkiewicz 2022: 765). The reaction can be quite

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argument that the Swedish state violated Article 8 of the European Convention, which says that states must actively provide people with the necessary information so that they can assess risks to life and health, and that they only implement pressure for vaccination if there is a strong social need. A decision in favour of the families would, they claim, finally confirm the state's responsibility for the vaccination injuries. The legal case of the patient ‘John’ filing charges and winning against the UK government is one of the most well-known <https://www.theguardian.com/science/2017/feb/09/ministers-lose-fight-to-stop-payouts-in-swine-flu-jab-narcolepsy-cases> (accessed on 2023-03-14). Several legal cases have also taken place in Ireland, in favour of the plaintiffs <https://www.irishtimes.com/news/crime-and-law/courts/high-court/girl-who-claims-to-have-sleep-disorder-after-swine-flu-jab-gets-1-325m-1.4737586> (accessed on 2023-03-14).

<sup>11</sup> [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2012453-om-register-over-nationella\\_sfs-2012-453](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2012453-om-register-over-nationella_sfs-2012-453) (accessed on 2023-03-14).

understandable. Researchers, in general, wish to defend democratic values and scientific knowledge, but this risks interfering with social science researchers' aim to conduct open-minded investigations of individuals and their beliefs. It may prevent them from recording the root causes of citizens' reluctance to receive COVID-19 vaccinations. The goal of our curiosity driven approach is to find out more about the world and to understand it better, and with Drażkiewicz, we are convinced that a compassionate approach in the long run will lead to better understanding of anti-vaccine attitudes and their probable causes among individuals and groups. If the results of this research lead to increased vaccination uptake in the future, this is of course very positive, but this is emphatically not an aim of the research.<sup>12</sup>

Furthermore, we identify Bernice Hausman's research as contributing to similar lines of inquiry, especially in her book *Anti/Vax: Reframing the Vaccination Controversy* (2019, thus published before the pandemic). Concerning the recurring claims, in both academic literature and the public debate on anti-vaccination sentiments, that the so-called anti-vaxxers are, in fact, denialists who suffer from some kind of cognitive delusion,<sup>13</sup> Hausman asks the question, "What if people's beliefs are simply, and basically, different?" (Hausman 2019: 107). Belief in scientific evidence is not a given, she writes. Belief is a contextually bound cognitive state, which means that culture provides us with a more fruitful theoretical framing for health beliefs than psychology "because attention to culture forces us to identify the specific concerns that people have and understand how those concerns are related to lived experiences" (Hausman 2019: 108). The work of Andrea Kitta (2012), Stuart Blume (2017), Maurizia Mezza (Mezza and Blume 2021), Heidi Larson (2020), Maya Goldenberg (2021), Kaisu Koski (Koski and Holst 2017), and Mia-Marie Hammarlin (2022) are also worth mentioning in this regard. Drawing on a variety of empirical sources and theories, they refrain from describing citizens who are sceptical of vaccines as a strange group of people who are not capable of interpreting facts correctly. Instead, they highlight the challenges that immunisation business, technologies and politics will have to contend with now and in the future, such as a growing disbelief in modern medicine among certain groups (Koski and Holst 2017), a lack of transparency regarding reported adverse effects on the part of vaccines (Mezza and Blume 2021), the interconnection between distrust in

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<sup>12</sup> To problematise the idea of compassionate anti-vaccination studies, and starting with ourselves, we would like to stress that we strive to be compassionate toward all interlocutors that we encounter in our academic endeavours. See Harambam (2020: 227–239) for an interesting discussion on these questions.

<sup>13</sup> E.g., the MD Saiful Islam and colleagues suggest what they call "cognitive inoculation" against misinformation to improve vaccine adherence (Islam et al. 2021).



vaccines and distrust of the governments that promote them (Larson 2020; Hammarlin 2022), the relationship between distrust in vaccines and distrust of the billion-dollar pharmaceutical industry (Blume 2017: 117–124; see also Harambam 2020), and how the idea that so-called public ignorance of science prevents citizens from making rational and mature decisions was established to begin with (Goldenberg 2021: 21–40; Blume 2006; Vanderslott et al. 2022).

## 2.1 Illness narrative typology

To better understand what the Flashback members talk about when they critically discuss COVID-19 vaccines, we dovetail this compassionate approach, outlined above, with the sociologist Arthur Frank's illness narrative typology. In line with Hausman (2019) and Koski and Holst (2017), we argue that illness stories are told between the lines in vaccine-hesitancy stories and that they are worth listening to. Illness stories are told not just about the body but also through the body, a body that is certainly not mute but, rather, speaks about experiences and memories of pain, loss, sorrow and fear.

While Frank pays attention to people's personal stories of physical and psychological experiences of illness, we will mainly analyse the Flashback commentators' *ideas* of illness, that is, their conceptions and presumptions surrounding disease and health that are being explicitly or implicitly expressed in the COVID-19 vaccine-critical comments. The Flashback texts are short, generally 5–20 lines, but after putting them together, they form somewhat coherent narratives. In such cases, Frank's typology helps us to explore "the naming story" (Frank 2013: 75), a story that occurs in many individual narratives, which reverberates in society and culture at a certain time and place.

To briefly summarise, Frank explores illness narratives through three main intermingled types: *the restitution narrative*, *the quest narrative* and *the chaos narrative*. The restitution narrative centres, to a higher degree, on health rather than illness, as captured by the following basic storyline: "Yesterday, I was healthy; today, I'm sick, but tomorrow, I'll be healthy again" (Frank 2013: 77). The quest narrative meets suffering head on. In it, illness is seen as a fundamental experience in life. A belief that something can be gained from the illness experience is entertained, in which suffering can be seen as a journey that becomes a quest, leading to personal development (Frank 2013: 115). A sense of purpose, meaning and control comes to the fore in stories of this kind, capturing the ill person as a subject who experiences, feels and acts upon the illness. As we see it, these two narratives – restitution and quest – function as vulnerability management tools; they promote a belief in the body's self-healing capacity and a sense

of control, hope and meaning in relation to illness, which is, in fact, inherently and indisputably characterised by uncertainty.

In comparison, the chaos narrative is a non-story in today's Western medical technocratic culture in the sense that it is rarely being told publicly, as it reveals modern medicine's limitations and life's inherent vulnerability and unpredictability (Frank 2013: 97). It opposes the restitution and quest narratives by replacing hope and meaning with futility and passiveness. Here, the body is subject to incurable illness and eventually dies. Illness and disease are the ultimate embodiment of the contingency of our existence, effectively contradicting the modern idea of the possibility of rationally controlling and predicting every aspect of our being (Frank 2013: 30f).<sup>14</sup> Moreover, all stories have an inherent social aspect. They are told to someone, whether that someone is immediately present or not (Frank 2013: 3). They also encompass cultural aspects; illness stories that are encapsulated in vaccine hesitancy narratives may teach us something about both the present time and past events and traumas. The *body-self* is a concept that we use, suggesting a rejection of the historical dualism between mind and body, as well as between culture and the individual body (Frank 2013: 41).

So, to sum up, while the main focus in this article is on vaccine hesitancy, we use illness narrative theory to provide us with analytical tools which help us capturing the meaning with what is being said about COVID-19 vaccines in the Flashback discussion threads.

### 3 FLASHBACK FORUM

With its roots in a punk fanzine from the 1980s, Flashback began its path in 2000 (Hannerz, Burcar Alm and Wästerfors 2022). It still carries characteristics of being edgy by providing a space for unfiltered discussions. Flashback is open in many respects, first of all, anything can be discussed (crime, politics, cooking, gaming, parenting et cetera), second, the forum's main principle is freedom of speech and a lack of censorship (Uhnöo and Ekbrand 2017: 126–151), third, registration is free and, as long as one claims to be over 18, anyone with a computer can read and participate in the discussions (Hannerz, Burcar Alm and Wästerfors 2022). Compared to, e.g., Reddit, one can note that Flashback is not owned by a global media company.

The rather frequent use of racist and misogynist language is a characteristic feature, as a consequence of which Flashback has a disputed

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<sup>14</sup> However, there is a growing body of research that investigates severe illness and death experiences that are being shared through social media. See, e.g., Amanda Lagerkvist's (2022) contribution within this area.

status in Sweden, but it has also become a well-known and, to some extent, influential platform, thus, attracting extreme discourse while, at the same time, being open to the mainstream (Ulver and Laurell 2020: 482). However, only a small proportion of users visit the forum on a daily basis.<sup>15</sup> Flashback's popularity, availability, and its fusion of mainstream and extreme political discourse are the main reasons we chose to study vaccine discussions here; we had good hopes of finding vaccine hesitancy expressions at this commonly argumentative platform.<sup>16</sup>

When it comes to the style of writing we may add that there is no app for mobile phones, and emoticons are not very common in the discussion threads. The most frequent way of responding to one another is to use the quote function; copying a piece of text from another member marked in a darker nuance of grey and writing a comment or a question underneath it so that everyone can see who is in conversation with whom, consequently promoting dialogue. Upon entering the webpage, commercial banners blink, and mostly satirical avatars are displayed to the left in the discussion threads. We refer to the communication on Flashback as conversation or talk (rather than text), which are the words the members themselves use.

We decided to investigate the three most popular Flashback discussion threads about COVID-19 vaccinations that we could find at the time of the data collection. The biggest of them has an explicit vaccine critical title while the other two have more neutral titles. In total, we study close to 11,000 unique posts. The time period for the entire dataset was from 2020-09-09, when one of the threads started,<sup>17</sup> until 2021-05-14, when activity began to slow down. Thus, the period includes the rollout of COVID-19 vaccines in Sweden and elsewhere.<sup>18</sup> Informed consent in this

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<sup>15</sup> Every third Swedish citizen uses Flashback, but only one percent of these use the platform on a daily basis according to the report *Svenskarna och internet* [The Swedes and the internet], by Internetstiftelsen (2018). In comparison, Instagram, Snapchat and Facebook are, to a high degree, used on an everyday basis. [https://internetstiftelsen.se/docs/Svenskarna\\_och\\_internet\\_2018.pdf](https://internetstiftelsen.se/docs/Svenskarna_och_internet_2018.pdf) (accessed on 2023-03-14).

<sup>16</sup> In addition, studies confirm that anti-vaccination views are widely and internationally shared on the internet (Johnson et al. 2020)

<sup>17</sup> The other two began in November and December 2020.

<sup>18</sup> In January 2021, the vaccine from AstraZeneca (later named Vaxzevria) was given to healthcare providers. In February of the same year, it was distributed to elderly citizens in nursing homes. In March 2021, the Public Health Agency of Sweden decided to stop using this vaccine, due to an investigation by the European Medicines Agency concerning blood clots with low blood platelets as a severe but rare potential side effect, which was later confirmed, leading to new recommendations for citizens under 65 years of age. In parallel, so-called mRNA-vaccines from Pfizer-BioNTech and Moderna were

case has not been possible given that the threads involve hundreds of users moving in and out of the discussions (Sveningsson Elm 2009). We have handled this through the following measures: we provide neither the full titles of the threads nor the aliases used by the posters, following Fiesler and Proferes' (2018: 10) suggestion that "publication of user identity should only occur when the benefits of doing so clearly outweigh the potential harms, or with user permission". All quotes are provided as translations from the original Swedish into English. In order to further preserve the members' anonymity, without interfering with the meaning of the discussions, we made some very small changes to the translations so that they cannot be easily translated back into Swedish again. Furthermore, the members' identities are successfully protected by the forum itself.

#### 4 MIXED METHODS APPROACH

To enable the analysis of close to 11,000 posts, we chose to follow an explanatory, sequential mixed methods design composed of two consecutive phases (Ivankova, Creswell and Stick 2006; Harrison, Reilly and Creswell 2020; Chang et al. 2021). This type of design incorporates the quantitative and qualitative findings in order to create more robust results and provide greater depth than either singular analysis would (Fetters et al. 2013). Initially, we quantitatively analysed the data using natural language processing techniques, viz. sentiment analysis and topic modelling. Second, we built on those findings in a qualitative follow-up study of the most voluminous thread – some 4,500 comments – that had a more explicit vaccine-critical title as compared to the others. We performed this study manually using a qualitative data analysis program. Using this tool, we created so-called nodes to obtain an overview of what was meaningfully being discussed in this particular thread. The nodes were developed into a profound narrative analysis, as described in detail below.

Sentiment analysis (Pang and Lee 2008) is the process of extracting and analysing subjective judgments and opinions expressed in a text to determine the author's attitude towards a particular topic – it could be a product, an event, or health interventions (On et al. 2019; Fetters and Molina-Azorin 2021) – i.e., if it is positive, negative, or neutral. We relied upon a lexicon-based approach to identify the sentiments using an in-house Swedish translation of the VADER sentiment analysis tool (Hutto and Gilbert 2014). We performed the analysis on each post to identify the positive, negative, or neutral sentiments, and revealed that out of all posts, more than half had negative sentiments (from 61.4% to 54.2%), with lower

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added to the programme in 2021, <https://www.folkhalsomyndigheten.se/> (accessed on 2023-03-14)

numbers for neutral sentiments (from 23.7% to 21.3%) and positive sentiments (from 17.3% to 22.1%). On this basis, we deem it probable that most commentators participate in the discussion threads with the purpose to criticize the COVID-19 vaccines, potentially belonging to the small minority in Sweden who hesitate to take, or refrain from taking the vaccinations.

After this, we used topic modelling (TM), a machine learning technique that automatically identifies so-called topics in a given data collection. Topic modelling offers an alternative to qualitative coding for textual analysis of large text collections. According to Chen et al. (2023), topic modelling can be applied to (i) gain a quick overview of the major contents from large unstructured, text collections by transforming a large sample of text into a much smaller set of topics; (ii) provide a new lens for scholars to identify patterns that would otherwise be undetectable with manual coding alone from a massive number of texts; and (iii) extract certain meanings from the text data. Moreover, the generated topics lack context, therefore the qualitative analysis provides the means to manual screening, interpretation and labelling each topic by inspecting the words and the documents they are contained in.

The particular variety of TM used for our study is based on an algorithm called *latent Dirichlet allocation* (LDA), which is widely used for TM and the statistical analysis of textual data (Blei, Ng and Jordan 2003). In this approach, each text – a post in the forum – is treated as a mixture of topics, and each topic as a mixture of words, which also allows posts to be topically overlapping. The input for a TM algorithm is typically a collection of text documents, the number of topics that the algorithm is expected to identify in the collection and a number of parameters used to fine-tune the topic grouping. Conceptually, TM assumes that a topic consists of a set of words, while a document consists of a mixture of topics, and the same word can appear in multiple topics with different probabilities (Reisenbichler and Reutterer 2019).

Before applying the TM algorithm, a number of pre-processing steps are typically applied to the text collection. In our case, meta-information, such as HTML tags, was removed, as were stop words;<sup>19</sup> all words were converted to lower case, and a number of collocations and phrasal verbs with specific meanings were concatenated into a single word in order to improve the results. Examples of the latter are the multiword expressions<sup>20</sup> *great reset*, *astra zeneca*, *big pharma* and *spruta in 'to inject'*. Finally, the text

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<sup>19</sup> Stop words are common (function) words, such as *the*, *of*, *and*, *that* and *is* (in English), which do not contribute to text content. In our TM study, the stop words are in Swedish, of course.

<sup>20</sup> Note that Swedish social-media language contains a large number of English expressions.

words were also lemmatised, i.e., the inflected forms of a word were reduced to its lemma, or dictionary form. This step also included the normalisation of spelling variants, such as *antivaxxer*, *anti-vaxxer*, *antivaxxare* and *antivaxer* to *anti-vaxxer*.

We begin with a presentation of the results of the TM analysis.

## 5 TOPIC MODELLING ANALYSIS (ZOOMING OUT)

As earlier mentioned, TM has no means of providing the meaning of topics, therefore we define the topic labels by determining their sense manually, that is, via an inspection of the topic word sets. Moreover, there is no “ground truth” with which to compare topic modelling results, and as such, a topic cannot exist without human interpretation. In the mixed research group – consisting of language technologists and experts in qualitative methods – we discussed the potential topics at length, building on our theoretical knowledge, leading up to five indicative topics with manually determined labels and words with high probabilities of belonging to the topic (Table 1).

**Table 1. An overview of the TM results (presentation format: English gloss [Swedish word]). The figures after each topic indicate the probability of the topic within the entire dataset.**

Topic Modelling	
Manual labels	Top-10 words with highest probability in the topic
<b>Tone/sentiment</b>	scared [rädd], shit/crap [skit], pandemic [pandemi], fucking [jävla], dangerous [farlig], idiot [idiot], understand [förstå], fuck [fan], chance [chans], propaganda [propaganda]; 0.10925152
<b>Freedom issues</b>	force (verb) [tvinga], travel [resa], refuse [vägra], Swedish [svensk], require [kräva], money [pengar], voluntary [frivillig], state [stat], coercion [tvång], vaccine pass [vaccinpass]; 0.10775140
<b>Truth seeking</b>	write [skriva], source [källa], science [vetenskap], anti-vaxxer [anti-vaxxer], argument [argument], post (noun) [inlägg], facts [fakta], information [information], conspiracy theory [konspirationsteori], scientific [vetenskaplig]; 0.10280961

<b>Power issues</b>	world [värld], state [stat], tin foil hat [foliehatt], population [befolkning], media [media], government [regering], to trust [lita], money [pengar], authority [myndighet], responsibility [ansvar]; 0.09912641
<b>Body issues/side effects</b>	problem [problem], vaccination [vaccinering], be affected [drabba], to test [testa], narcolepsy [narkolepsi], swine flu [svininfluensa], injury [skada], medicine [läkemedel], serious side effect [allvarlig_biverkning], side effect [biffekt]; 0.09572965

Even if presented as five separate topics, they are obviously interconnected. For example, bodily autonomy seems to be an important theme across a large part of the dataset. The topics suggest different threats to bodily safety and freedom, such as travel restrictions, laws, governmental force and adverse vaccine effects. We also note that it is acceptable to swear, perhaps even expected, which puts the results from the sentiment analysis in a more meaningful light, but it is also common to laugh out loud, it seems. This laughter is, considering the subject that is being discussed, likely ironic, which, again, says something important about the sentiment analysis; a positive attitude can be expressed ironically. As other Flashback analyses have shown, the posters' criticism is directed upward, towards the elite: the state, the government and the established media (Ulver and Laurell 2020: 485–487). Additionally, the posters seem to actively refer to sources and facts to promote their ideas.

We interpret the overall meaning of the five topics listed above as follows: the people engaged in these COVID-19 vaccine critical conversations stand together against the elite, who want to restrict “our” freedom and force “us” to take a potential poison, which will be injected into “our” healthy bodies, and we may become incurably sick due to the vaccine, exhibiting what Ulver and Laurell (2020: 486) label “self-positioning as the marginalized Other [which] continuously takes on bitter expressions on the forum”. Not surprisingly, the mass vaccination is dealt with as both a political problem (force/coercion/elite/state) and a medical issue (narcolepsy/healthy/immune system). We also observe that the commentators do not seek harmony or acceptance, and they, seemingly, do not advocate trust between citizens and authorities. Instead, they exhort others to think for themselves. In line with Ulver and Laurell, we argue that this particular platform, at least in threads devoted to political debate, amounts to a milieu that fosters feelings of animosity, “giving credence to the interpretation of [vaccine] refusal as an act of political defiance” (Wollebæk et al. 2022: 18). The TM overview also reveals feelings of

*vulnerability*, we argue. The posters underscore the need to protect oneself and fight back. It may be argued that they express a fear of being subjected to medical experiments, in which memories from the swine flu pandemic seem to play a certain role, as we will delve more deeply into in the next section.

## 6 ILLNESS NARRATIVE ANALYSIS (ZOOMING IN)

As explained above, vaccine criticism usually includes complex ideas of illness and health (Koski and Holst 2017; Hausman 2019), therefore, we will draw upon Frank’s illness narrative typology (Frank 2005, 2013) to better understand the Flashback posts. In this section, we study the biggest of the three threads. Building on the TM analysis and Frank’s typology and with the help of a qualitative data analysis program, three interrelated nodes, divided into four to five subcategories, were found (Table 2), which we will investigate closely. The first one, “authority criticism”, both reflects and develops the topics “freedom issues” and “power issues”. The two other nodes, “vaccines as unnecessary” and “unsafety of the vaccines”, deepen the understanding of the topics “body issues” and “side effects”. The remaining two topics, “truth-seeking” and “tone/sentiment” seem to have a more all-embracing function: the first by encompassing the posters’ fact-searching activities, and the second by capturing their style of talking to one another, thus, they are presented as topics in their own right but are also integrated in all topics and all nodes.

**Table 2. An overview of the qualitative analysis.**

Nodes	
<b>Authority criticism</b>	big pharma; government criticism; mass media criticism; criticism against medical institutions; conspiracy theories
<b>Vaccines as unnecessary</b>	the pandemic is magnified; not all have to take the shots; relying on natural immunity; the vaccines are ineffective
<b>Unsafety of the vaccines</b>	not tested enough; swine flu; narcolepsy; other side effects and injuries; mRNA technology; gene therapy; vaccine as poison

We will begin with the first node, authority criticism, which contains critique of the pharmaceutical industry, sometimes referred to as *Big*



*Pharma*, perceived as ruthlessly profit driven. It encompasses globally established, neoliberal-critical ideas among vaccine reluctant individuals and groups (Harambam 2020: 72–76). Furthermore, widespread criticism directed towards the Swedish authorities and experts, such as the state, the Public Health Agency, civil servants and top politicians, is included here. This leads us, step by step, further into the other nodes, but to be able to capture the meaning with the discussions we need a bit more freedom, we believe, and will therefore organise the narrative analysis through more open and explorative subtitles.

### 6.1 “It’s my body!”

Even though vaccines of all kinds are voluntary in Sweden, notions of the need for defiance against the government and the authorities’ recommendations are frequent in the thread, reflecting a suspicion that they want to, or will in the end, force all people to take vaccinations against COVID-19. ‘The state’ (*staten*) is used in order to pinpoint this fighting-back discourse, underscoring the ruthless power it has over peoples’ lives, according to the Flashback members. Together with other expressions, such as *Tegnell* – during the pandemic the chief epidemiologist of the Public Health Agency of Sweden Anders Tegnell became the most well-known civil servant and physician in Sweden – ‘authority’ (*myndighet*) and ‘the government’ (*regeringen*), ‘the state’ points toward the conviction that individuals lack control of their own lives. Some typical examples are as follows.

Generally, I am sceptical towards everything that the state says that we ‘have to’ do. When they put such an effort into convincing us that it is ‘for our own good’, then there is a hidden agenda behind it. Thanks, but no thanks.

I’m just amazed that somebody so blindly can trust the daddy state and its propaganda. But I guess that voluntary guinea pigs will always be available.

You idiots that don’t understand that a profit-driven society never will focus on what is best for you – you need to learn basic logic. It’s possible to silence the minority as long as the majority is pleased. Enjoy your vaccines! PS. Don’t forget your 300 booster doses!

Conceivably, what is nurtured here is *motivated reasoning* characterised by the central goal of maintaining a valued identity, specifically membership in social and cultural groups (Goldenberg 2021: 45–49). In this sense, however loosely composed, the individuals expressing criticism of COVID-19 vaccines in this particular thread *do* identify with one another, i.e., as

critical Flashback members, impugning the COVID-19 narrative imposed from above. Vaccine hesitancy “is about much more than disliking vaccines; it signifies a constellation of attitudes and behaviours comprising a social identity” (Goldenberg 2021: 46; see also Klintman 2019). Our TM analysis is good at showing how this social identity is being formed through, among other things, a coarse and ironic tone of voice, which we regard as a competence needed to become a part of the Flashback community, at least in discussion threads of this kind.

An urgent need for resistance is expressed, which can be interpreted both as restitution and quest illness narratives. In order to stay unvaccinated and, thus, healthy, the members resist what they identify as propaganda and persuasion attempts, nurturing well-spread ideas among vaccine critical individuals of natural healing without medical interventions (Koski and Holst 2017). The quest narrative materialises itself as a sort of crusade against the powerful elite.

What resistance in relation to illness points to is suffering; the two go hand in hand, Frank claims, and “the body’s suffering during illness creates a need for stories” (Frank 2013: 169). So, if resistance and suffering should be regarded as an inseparable couple, in what way do the Flashback resistant driven members suffer, and from what do they suffer? Arguably, they experience feelings of powerlessness, of not being able to control one’s own body. “It’s my body!” is a common remark, an expression of “embodied paranoia” (Frank 2013: 172), that is, the fear of becoming a victim of not only natural threats, such as natural disasters and diseases, but of medicine itself when bureaucratic experts and physicians, such as Anders Tegnell, have the power to turn bodies into cases, potentially causing suffering. When people feel that decisions about them are made by strangers, they may feel victimised (Frank 2013: 172).

The Flashback members, we argue, negotiate feelings of disempowerment by drawing a line between “my body” and “the state”, and by seeking support among likeminded citizens. Together, the members feel less vulnerable. And they seem to see themselves as part of a grander and more challenging project. The dispute was perhaps never only about the vaccines or the science and the companies that produce them, but about complicated societal matters encompassing concerns about how medical technology and technology in general shape our lives, increased privatization of essential health services, growing income gaps and public health injustices (Goldenberg 2021: 106; Hausman 2019).

It may also be “scientised politics” that the posters attack; “the evidence-based everything” movement that swiftly transformed social science research on health and health care from the early 1990’s and onwards (Goldenberg 2021: 94). But “[t]he evidence-based promise of moving decision-making past partisanship and personal preference,

though undoubtedly appealing, is not fully realized by silencing value disputes”, Maya Goldenberg writes (2021: 96). Seen as a value dispute it could be argued that vaccine hesitancy is good at exposing the limits of the value-free ideal of science and scientised politics, and new medical technology in particular seems to become a projection surface for the debate. A dichotomy takes shape, where romantic ideas of natural immunisation, and a positive view upon nature in general, are contrasted against modern, liberal values encompassing ideas that technoscience and a free market will make the future brighter.

## 6.2 Fearing mRNA-vaccines

Even if the Flashback members fear vaccines in general, they are most hesitant regarding so-called new vaccination technologies, referred to as poisonous. We will attempt to put this into perspective through a fun and thought-provoking quote by an elderly woman from North Africa, which is found in Pierre Bourdieu’s *Outline of a Theory of Practice*. The woman says, “In the old days, folk didn’t know what illness was. They went to bed and they died. It’s only nowadays that we’ve learned words like liver, lung, stomach, and I don’t know what!” (Bourdieu 1977: 166).<sup>21</sup> The premodern society was characterised by harsh, sudden and surprising illness and death. A seasonal flu or cold – due to poverty, hygiene deficits, cramped housing accommodation and a lack of medical knowledge – could develop into a bacterial, dangerous and sometimes deadly pneumonia or other severe disease. What the quoted statement by Bourdieu’s interviewee captures is the shift from premodern to modern notions of illness, which she finds ambiguous, puzzling and maybe even repugnant.

In comparison, when some of the Flashback members, living in the 21st century, seek to understand a new viral pandemic, they talk about it using pseudo-professional terms, adopting a language that seems to be familiar to most members. No one openly protests in the thread when members use technical abbreviations such as mRNA, DNA and SARS or medical terms such as ‘autoimmunity’ (*autoimmunitet*), ‘nanotechnology’ (*nanoteknologi*) and ‘adjuvants’ (*adjuvanter*).<sup>22</sup> Some of these medically and technically oriented comments rely on serious sources but, in the end, tilt toward conspiracy-theory thinking. Three typical examples:

mRNA has never been used on humans before and acts like an ‘operating system’ in the form of nanoparticles, in other words chips. It is designed so that it can plug and play interchangeably with different programs. In

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<sup>21</sup> We owe this quote to Frank (2013: 5).

<sup>22</sup> An adjuvant is a substance that is used to increase the efficiency of certain vaccines.

our case, the ‘program’ or ‘app’ is the mRNA drug. The vaccine is emergency use authorised by WHO and FDA.

The crap Pfizer is pushing is freaking gene therapy that messes with your cells in a way we don’t yet have a clue of what the long-term effects will be. If you want to be a guinea pig, just go ahead. It’s entirely up to you.

RNA vaccines affect your DNA structure, so, technically, you will not be the same person you were before you took the vaccine, just so you know.

In particular mRNA, which is sometimes referred to as RNA, has become a symbol for technological medical “achievements” that cannot be trusted. Sometimes the words are mentioned together with words such as ‘guinea pig’ (*försökskanin*), indicating that the Public Health Agency and the physicians working there – who are controlled by the pharmaceutical industry according to some comments – use innocent people to test futuristic, unreliable vaccines that may cause life-long disturbances of the immune system. Here, as the TM analysis also shows, the commentators search for the “truth” by sharing facts and figures, displaying their knowledge to others. And they can come across as quite sure of themselves. Explicitly and implicitly, they express a confident attitude, seemingly believing that they know more about these technologies than epidemiologists and other vaccine experts do.

The handling of mRNA fear in the discussion thread reveals an ideological shift in society, we argue. In the countries of the industrial North, vaccination hesitancy a century ago was fuelled by class-consciousness (Durbach 2005), while today, the vaccine question concerns the right to make a so-called individually informed choice based on knowledge, a right and responsibility that has been given growing legitimacy by a new rhetoric of healthcare (Blume 2006: 639). This rhetoric, some claim, took shape during the AIDS epidemic of the 1980s, when the health authorities were pressured to respect individual privacy and rights; this was a sign of an ideological shift toward individualism and *gesellschaft* (Bayer and Colgrove 2003). In relation to this change in society, Stuart Blume poses the question: “Isn’t a critical stance towards vaccination, and hence the possibility of alternative viewpoints, a logical consequence of this ideological shift?”. He continues:

The market working that is encouraged elsewhere in the health care system is surely in tension with the demands made on behalf of the public health here. Decades of emphasis on personal rights and responsibilities have encouraged growing number of educated parents, many of whom have already learned to express their preferences in opting for natural childbirth for example, to reason for themselves. For such parents the

vaccination literature available and the attitudes of practitioners are deeply dissatisfying (Blume 2006: 639).

Blume points to an inconsistency between The National Health Service policies' emphasis on patients' rights to informed consent and practices of mass-vaccination that risk failing to respect those rights, or so it is interpreted by people who are critical of vaccines. For example, COVID-19 vaccination certificates were viewed by many involved in the discussion thread as a coercive measure, undermining the agreement of informed consent and freedom of choice. It is reasonable to believe that, *if* some of the Flashback members engaging themselves in this conversation decided to take the COVID-19 vaccination, they are likely to demand a protein-based vaccine, underscoring both their (professed) knowledge about mRNA vaccines and their personal right to choose for themselves.

The technocratic expert jargon in the Flashback discussions, as exemplified above, is also an illustration of how illness stories today, at least to some extent, are being replaced by fragments of information, and the development of modern medical technology has a great deal to do with this (Frank 2013: 163). People have successfully learned to deliver technical accounts of their suffering – incoherent stories constructed around chemical compounds, cells, molecules and medical treatments – describing the factual cause and progression of the disease without expressing the multiple shocks of illness in everyday life (Frank 2013: 6). Bourdieu's interviewee would not be able to write something similar to the Flashback quotes above, lacking a language for her hereditary material, in the form of cells and genes, and the diseases they might bring. This indicates a knowledge struggle where “[t]he story of illness that trumps all others in the modern period is the medical narrative”, which means that the story told by the physician becomes the story against which all other illness narratives are measured (Frank 2013: 5). Thus, we suggest that the “flirting” with the expert role, exemplified above, should be seen in this light, namely as a means to reclaim the knowledge of one's own body and its suffering.

Another basic assumption we make is that, *if* people who strive to resist the mRNA-vaccines and diminish and even ridicule COVID-19 catch the virus and develop pneumonia as a consequence – a not uncommon form of disease progression – most of them will turn to traditional medical care for help. What we attempt to pinpoint here is that the sense of individual safety – “I trust in my immune system” – that is expressed in the discussion stems from the fact that there *is* professional modern healthcare around the corner when needed, thus drawing on the restitution narrative. We see this as an expression of a tacit belief in modern medicine that does not conform to the spiteful, antagonistic attitude of Flashback and its users' self-

positioning as the marginalised Other. Consequently, to conform to the cultural climate, this belief must be replaced by doubt.

### 6.3 Avoiding chaos

As can be seen in the TM and the nodes overviews, words such as ‘narcolepsy’ and ‘swine flu’ signal an awareness of the chronic neurological disease that occurred as a very unusual but severe side effect of the mass vaccinations in 2009–2010 (Lundgren 2015a; Aasgaard Jansen 2018). It is the most common example of adverse vaccine effects in the text corpus. When narcolepsy, the swine flu or Pandemrix (the swine flu vaccine) are commented on, the words are used symbolically or metonymically, i.e., the Flashback members mention them briefly, without elaborating on them, but, at the same time, reminding the reader of the “devastating results” of the mass vaccination at that time. We will illustrate this with a few examples that, together, summarise the general mode of using the words.

Sweden bought half of the whole world’s production of the swine flu vaccine in 2008–09 for distribution in the schools. Afterwards, it was these snake oils that destroyed the lives of so many children and young adults.

There were surely about 500 children that developed narcolepsy because of the swine flu vaccine. There are only a couple of children who have been hit badly by COVID, so if this vaccine ends up with the same result, COVID is, in comparison, safe.

I wonder if the relatives to the approximately 400 that developed narcolepsy because of Pandemrix are eager to try this vaccine out...

When these topics are referred to in the Flashback conversations, distrust of both the knowledge claims of modern medicine and the legitimacy of the public health authorities’ measures to fight the coronavirus is displayed. Many types of feelings are expressed, such as fear of suffering, empathy, fellowship and anger. Typically, the reader is provided with little information about narcolepsy. Only one comment among the 1,493 in the thread that focuses on side effects and narcolepsy describes (second-hand) experiences of the illness.

I have a good friend who took the swine flu vaccine. Suffers now from narcolepsy. A happy-go-lucky 15-year-old whose life was devastated. We can sit together at a restaurant, and his face plunges into the food, and he sleeps for a quarter of an hour.

These findings encourage us to try to understand this lack of words, which we will return to below. In her work on narcolepsy and the swine flu aftermath, Lundgren investigates how parents of the children and young

adults who were affected by the disease handled the situation 4–5 years after the swine flu pandemic outbreak. She sheds light on how they shaped their experiences of this side effect into a political and critical narrative, not least through the formation of the Association for Narcolepsy<sup>23</sup> with the goal of lobbying for more effective medication and economic compensation (Lundgren 2015a). Furthermore, she illustrates the suffering that the affected children and their parents have to cope with every day, such as sudden sleep attacks, cataplexies, paralysees and hallucinations. The school years are usually doubly challenging as the children find it difficult to keep awake during the daytime. As adults, they will be limited in various ways; there are professions that they cannot have and restrictions concerning one's driver's license. Needless to say, narcolepsy patients' social life can be rather limited due to the symptoms.

The narcolepsy narratives in Lundgren's research are intertwined with many others in public life. During the last decade, established media in Sweden have provided their audiences with many reports on narcolepsy affected teenagers, leading to a national awareness of a very rare neurological affliction that most people had never heard of before.<sup>24</sup> However, there are also other forms of public expression. Pia Dellson, an MD in oncology and psychiatry, has a son who developed narcolepsy after having taken the Pandemrix shot in 2009, at the age of six. Dellson has published a book of poetry about her experiences, *Sovsjuk: En mammadoktor skriver om narkolepsi* (2015) [Sleeping-sick: A mom doctor writes about narcolepsy]. In 2021, the Dellson family took the recommended COVID-19 vaccinations. It was as much a self-evident action as a difficult one, causing all sorts of emotions. At this time, Dellson began to poetically reflect on the potential interconnections between the mass-vaccinations during the swine flu and the COVID-19 pandemic.<sup>25</sup> She writes:

*It is not ignorance  
that makes people hesitate.  
It is the knowledge  
of how badly things can go  
and how lonely you are then.*

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<sup>23</sup> <https://www.narkolepsiforeningen.se/> (accessed on 2023-03-14).

<sup>24</sup> See, for example, Linnéa Persson's story in public service channels, in which Pandemrix is discussed in relation to the new COVID-19 vaccines: <https://www.svt.se/nyheter/lokalt/halland/linnea-fick-narkolepsi-av-pandemrix-nutveksam-infor-covidvaccin> (accessed on 2023-03-14).

<sup>25</sup> These poems are still unpublished, and shared here by the author's permission, in translation from Swedish to English by Pia Dellson.

In another poem, she writes:

*For ten years, the narcolepsy  
has been a private grief of ours  
Now, the shadow of it  
is a problem  
nationwide.*

And the last example:

*My sixteen-year-old son  
takes narcotic medication  
three times a day  
and three times a night.  
He will never be able to  
work full-time.  
And the state has compensated him  
with 5 000 euros  
A risk like that you only take  
once a generation.*

What is at stake here is a *collective memory formation* that has been ongoing since 2010. This memory-formation process, we believe, was reinforced by the COVID-19 pandemic a decade later, which the Flashback conversation, the many media reports and Dellson's poetry exemplify. In contrast to both the restitution narrative and the quest narrative, the illness narrative about narcolepsy, as it takes shape in the Flashback thread, is an example of a chaos narrative; it is a *non-plot* in which the teller – the sick person – is not perceived as telling a "true" story. In Frank's (2013: 97) words, "the teller of the chaos story is not heard to be living a 'proper' life, since in life as in story, one event is expected to lead to another. Chaos negates that expectation." He even calls the chaos narrative a "mute illness" (2013: 97). What emerges here is the cultural tension between the collective memory formation regarding narcolepsy and the will to avoid chaos, i.e., a fearsome disease, not through taking the COVID-19 vaccines but by refusing them. On the one hand, the Flashback members seem to base their conviction on a presumption of a collective knowledge about narcolepsy, making details about symptoms unnecessary, as "we" are already aware of the life-long suffering that the disease may cause, underscoring the fact that it provides no room whatsoever for being "successfully ill". Consequently, it is a disease to fear, ultimately, as it may lead to social and cultural disintegration, which Dellson refers to as loneliness (Frank 2013: 64, 171). On the other hand, narcolepsy is an illness that is difficult to talk about and hear about because it is threatening, leading to a lack of words, a story that



“traces the edges of a wound that can only be told around” (Frank 2013: 98), which, in turn, makes the shape of the collective memory indistinct.

From the perspective of the Flashback members, narcolepsy is, no matter how unusual, a much more frightening disease than COVID-19, which, after all, is reminiscent of a regular cold or flu for most people who become infected. The elderly will naturally be sicker than children. The main purpose of regarding COVID-19 as a seasonal flu or cold is to understate the risks with the virus, and that one can recover from it with or without the support of health professionals and, most importantly, without having to take the shot (Karlsson et al. 2021). These are stories that fit well with the restitution narrative, building on contemporary Western cultural ideas that being healthy is the normal state, which illness temporarily interrupts, and that one can easily avoid the threatening narcolepsy chaos or other imagined neurological side effects by not taking the new ‘pushed through’ (*framstressade*), ‘emergency use authorised’ (*nödgodkända*) vaccines. This reasoning points to the so-called *omission bias* tendency, meaning that it may be easier to accept harm caused by not taking action than to actually do something, such as taking a shot in this case, and eventually become chronically ill as a consequence (Lundgren 2015b: 111; Bish et al. 2011: 6482).

In Frank’s vocabulary, these are actions of self-regimentation, indicating a disciplined body-self ideal type, distinguished by the effort to be in control. Through therapeutic regimens, orthodox medical compliance or alternative treatment, the response of such a body-self is to reassert predictability (Frank 2013: 41).

## 7 CONCLUSIONS

Further research on vaccine hesitancy should critically investigate the well-spread idea that poor public trust in vaccines is mainly a problem with the publics. Vaccine proponents often contribute to public shaming of vaccine hesitators, but are at the same time reluctant to admit problems in scientific governance (Goldenberg 2021: 169). This is not the way forward, we believe. Instead, we have suggested a compassionate approach to vaccine hesitancy, that is, at least to some extent, reasonable.

Through a mixed methods analysis, we have shown how vaccine hesitancy encompasses difficult and complicated matters, such as a fear of becoming disempowered and losing control over one’s body. A pandemic is, to a large extent, a political matter, one handled through safety measures such as laws, regulations and recommendations. The fact that these result in protests on the part of some citizens cannot come as a surprise to anyone, and there is something to learn from these protests, both concerning pandemic politics and the individual body, as well as the limits between them. Critically debating the possibility of rejecting the COVID-19

vaccinations is a concrete example of how individuals seek to manage the burden of doubt and feelings of insecurity in the face of the inherent contingency of the pandemic and life in general.

When the Flashback members use their voice, they do it in the role of aware citizens who have read and spread numerous sources of knowledge in their specific communities, thus expecting to be treated as individuals who may or may not give their informed consent to become vaccinated against COVID-19. This also points to the social identity aspects of vaccine hesitancy expressions in digital communities; by favouring a certain tone of voice, they resist the perceived vaccine coercion together, expressing both empowerment and disempowerment in relation to the authorities and the body-self.

We have also shown how a new pandemic may enhance memories of earlier pandemics. The mass vaccinations against COVID-19 triggered memories of the swine flu mass-vaccination, which, at the time of this writing, happened more than a decade ago. An awareness of narcolepsy as a rare but severe side effect is evident in the conversations. This neurological disease becomes an example of a chaos narrative that seems both necessary and difficult to talk about. This leads to further questions concerning authorities' (ethical) preparedness to openly report and discuss side effects, which we aim to investigate elsewhere.

We conclude that the Flashback members, on one hand, seem to know quite a lot about new vaccination technologies. They don the role of experts by using a medical scientific language, which may come across as impressive to others and comforting in relation to the body-self. On the other hand, they express a fear of new, "poisonous" vaccines, which they seek to avoid, and recommend others to do the same. This should be seen in relation to society's development toward a new rhetoric of healthcare, we have argued, in which public health premises during the last decades have been pressured to respect individual privacy and rights. An ideological shift towards individualism and *gesellschaft* in health care has taken place, which may indicate future challenges concerning trust for the pharmaceutical industry and medical expertise.

This shift also reveals more complex societal and political matters. Criticism against established science is easily detected in the material. When regarding vaccine hesitancy as a value dispute, a sort of dichotomy between what is categorised as natural and unnatural takes shape in the discussions, where so-called new medical technology becomes a projection surface. The Flashback members protest against science and scientised politics value free ideals in the late modern era by turning the question of vaccines into exactly that; a value loaded question. An imagined power struggle over the individual body is used as an emotionally charged symbol to lend meaning to the conflict.

We cannot take it for granted that techno-scientific modernity and democratic values and decision-making necessarily go hand in hand, certainly not if people feel that technoscience and big business are working together because of profit making in the first place, with dedication to the well-being of citizens being a secondary concern (Hausman 2019: 218).

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