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Losing trust: Processes of vaccine hesitancy in parents' narratives

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ABSTRACT

Lack of trust is central in becoming hesitant towards vaccines, but research on vaccine hesitancy lacks detailed examination of the processes of losing trust. Based on ethnographic interviews with 38 parents in Finland, we explore how and why they have lost their trust in vaccination.

We identified two paths to losing trust in vaccination. One was connected to mistrust – a cumulating suspicious attitude toward vaccines and related institutions. The other was associated with distrust – a more sudden loss of trust. We identified four ideal type narratives of losing trust: the *activist*, the *hesitant*, the *disillusioned* and the *negotiator*. The narratives of the *activist* and the *hesitant* were connected to mistrust. The *activists* were certain of their vaccination decisions whereas the *hesitant* parents were not. The narratives of the *disillusioned* and the *negotiator* were connected with distrust. The *disillusioned* parents had lost their trust due to adverse effects of vaccination and a lack of institutional support. The *negotiators* suspected adverse effects and were less certain about their decisions.

The article provides insight into the ways in which people lose trust in vaccination, which is crucial for supporting trusting relationships between vaccine-advocating institutions and the publics.

1. Introduction

In recent years, increasing concern has been raised about political distrust in the countries of the Global North. This distrust manifested, for instance, as criticism of governmental COVID-19 policies and noncompliance with pandemic-related public health recommendations, such as social distancing or vaccination. Trust has indeed become an important concept in analysing contestation of vaccination. Previous research has acknowledged the importance of trust in the processes of becoming vaccine-hesitant (MacArthur, 2017; Peretti-Watel et al., 2015). Furthermore, research strongly suggests that lack of trust is a central reason for hesitant attitudes towards vaccines (Benin et al., 2006; Brownlie and Howson, 2005, 2006; Deml et al., 2022; Hobson-West, 2007; Hornsey et al., 2020; Nurmi and Harman, 2022; Peretti-Watel et al., 2019).

In social research on vaccine hesitancy and in public health policy discourses, lack of trust in institutions that develop and promote vaccines is often understood as the problem of vaccine-hesitant individuals – they are seen as the ones who *lack* trust in the institutions of medical research or public health authorities (see e.g. Hausman, 2019). For example, the European Joint Action on Vaccination EU-JAV (2022) proposes that in order to increase public trust in vaccines, health authorities should follow the signals of increasing mistrust in social media and intervene. However, it has been suggested that generalised uses of the concept of trust in research may hinder analysis of vaccine hesitancy by discouraging specific questions about particular institutions' interests, performance or relationship with the public (Leach and Fairhead, 2007, 29).

Despite the centrality of (lack of) trust in explanations for vaccine hesitancy, trust as a concept is usually not formally defined in research on trust in vaccines, and there has been a disconnect between vaccine hesitancy research and wider health-related trust literature (Larson et al., 2018). This aligns with how empirical sociological research has often not thoroughly defined trust as a theoretical concept (Engdahl and Lidskog, 2014; Luhmann, 1988).

In this article, we ask *how and why vaccine-hesitant parents have lost trust in vaccination and vaccine-related actors or institutions*. Our aim is to deepen understanding of the processes of becoming vaccine-hesitant. The article is based on the narrative analysis of ethnographic interviews with 38 Finnish parents who opted out of some or all vaccines for their child(ren).

Recently, there have been calls to emphasise theorisations of trust rather than compartmentalising trust as one of the many reasons for vaccine hesitancy (e.g. Goldenberg, 2021, 113). We further argue that,

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specifically, research on vaccine hesitancy often lacks a thorough examination of the *processes* of losing trust in vaccines and how this creates and sustains vaccine hesitancy. In this article, we emphasise that it is not just lack of trust, but also experiences of *distrust* and *mistrust,* that should be examined in order to understand how and why parents settle upon delaying or refusing childhood vaccines. Our study contributes to the understanding of the ways in which people lose trust in vaccination, which is crucial in terms of supporting trusting relationships between vaccine-advocating institutions (public health institutions, governmental actors and the healthcare system) and the publics.

Public distrust in scientific expertise is rooted in broad trends such as the commercialisation of science and the framing of public issues in technical terms (see Engdahl and Lidskog, 2014). We suggest that losing trust is not solely an issue of vaccine-hesitant individuals causing a problem that needs to be solved. Rather, vaccine hesitancy and contested health topics in general channel broader social phenomena of increasing public distrust (e.g. Kennedy, 2019). For instance, in Italy, anti-vaccination campaigns have been aligned with populist political movements that fuel mistrust towards public healthcare and scientific authorities (Speed and Mannion, 2020).

While analysing vaccine hesitancy, it is important to note the historical, cultural and political context of building (mis)trust between the state and its citizens. In this study, the Finnish context allows for the processes of losing trust to be examined within a socio-political culture of high institutional trust. Finland also has high levels of vaccine uptake and vaccine-related trust, both of which remained fairly stable during the COVID19-pandemic (Tieteen tiedotus ry 2022; Väliverronen and Jallinoja, 2021). In general, political trust in Finland increased significantly during the first wave of COVID-19 (Kestilä-Kekkonen et al., 2022). Likewise, in comparison with other EU countries, Finns had relatively strong trust in the efficacy and safety of COVID-19 vaccines in the spring of 2021 (European Union 2021). Nevertheless, attitudes of suspicion and distrust in COVID-19 related public health measures and restrictions were reported in a significant part of the population (up to 14% in 2021) (Jallinoja et al., 2021). Compliance with COVID-19 recommendations has been linked to political trust, both in Finland (Kestilä-Kekkonen et al., 2022) and European countries in general (Bargain & Aminjonov 2020). Similarly, suspicious and distrusting attitudes toward governmental COVID-19 policies were associated with lower acceptance of COVID-19 vaccines (Jallinoja et al., 2021), and attitudes towards vaccines became slightly more polarised in Finland during the pandemic (Tieteen tiedotus 2022).

This article begins with a discussion of the concepts of trust, distrust, and mistrust, and an examination of how the theoretical clarification of these concepts can benefit analyses of vaccine hesitancy. After introducing our research materials and methods, we will present a typology of four different narratives of losing trust, discuss elements of mistrust and distrust, and address dimensions of certainty and uncertainty in the narratives.

2. Trust, distrust and mistrust in vaccines

Whether or not people trust in health systems, such as national vaccination programmes, is determined by complex interactions between the representatives of the health system, the medical system, and broader social systems (Meyer et al., 2008). In terms of vaccination, people need to trust, for example, the health authorities and their representatives, as well as the healthcare workers administering vaccines. In sociological literature, this kind of intersubjective trust has usually been separated from institutional (or generalised) trust, which deals with trusting more abstract entities such as the healthcare system (e.g. Giddens, 1991; Luhmann, 1990; Misztal, 1996). However, the concept of trust is more nuanced than this common dichotomy suggests, as it can involve connotations of faith, confidence, expectation, role performance and security (Jennings et al., 2021; Misztal, 1996). In sociology, trust should be seen as a relational and collective attribute rather than a form of faith, which has both psychological and religious undertones (Brownlie and Howson, 2005; Möllering, 2001, 2006; Lewis and Weigert, 1985, 968–970). In fact, many vaccine-hesitant individuals strongly question 'trust as faith' when it comes to making vaccination decisions, and emphasise other means of making choices (Hobson-West, 2007). Mistrust and distrust, then, become key components in the processes of becoming vaccine-hesitant. Moments and processes of losing trust are also empirically more easily accessible in the lived experiences of vaccine-hesitant people than the experience of trust as faith.

In empirical research, lack of trust in vaccines has often been conceptualised as a narrative of eroding trust in health experts and authorities, characteristic for late modern high-income societies. For example, Giddens (1991) has emphasised that the refusal of modern health technologies, such as vaccinations, means taking back control over one's own life in societies that are built on technoscientific expertise. However, a linear view presuming that a general trust in vaccination existed previously can be problematic (Leach and Fairhead, 2007, 36). It does not take into account the politicised criticism and opposition that has followed vaccination efforts since the first vaccination campaigns began in Europe (Durbach, 2005). Such a linear view also fails to acknowledge that acceptance of vaccination can stem from lack of choice rather than trust (such as when vaccine refusal has been sanctioned or children have been vaccinated without parental consent, both of which have historically occurred in Finland, see Laurent, 2017; Wasz-Höckert et al., 1963). Using the narrative of declining trust to explain vaccine hesitancy risks imposing a normative view of governmental public health efforts, painting them as technocratic and apolitical (Leach and Fairhead, 2007, 36).

Taking into account historical health movements critical of vaccines and vaccination policies, and the fact that historical vaccination compliance may be partly explained by "lack of choice, lack of knowledge, and obedience to authority" (Attwell et al., 2017), another way of conceptualising lack of trust in vaccines emerges. This perspective refers to a reflexively organised dialectic of trust and doubt in the context of medicine (Williams and Calnan, 1996, 1612), which makes it more understandable that attitudes toward vaccination are affected by awareness of historically, geographically and politically contextualised uncertainties or problems related to vaccines, medical research or pharmaceutical companies (Goldenberg, 2021, 130). Through this perspective, it is easier to approach suspicious and critical vaccination attitudes not only as a problem, but as a part of public engagement with expertise and science.

Even trustful attitudes toward vaccination may consist of complex elements rather than a simple position of trust. For instance, 'a will to trust' the healthcare system and its representatives can conceal anxieties regarding a medical treatment (Brown, 2009). If trust is about living in spite of complexity or reducing it (Luhmann, 1979), mistrust and distrust exemplify ways of living with complexity. Instead of viewing trust and distrust as binary categories, trust/mistrust/distrust should be seen as a family of concepts (see Jennings et al., 2021) in understanding the processes of losing trust in vaccination. Although mistrust and distrust are sometimes treated as synonyms (e.g. Ward and Coates, 2006), the concepts should be considered as analytically separate. Mistrust refers to cautious, doubtful, questioning and sceptic attitudes (Jennings et al., 2021; Lenard, 2008), a more neutral situation in which there is neither trust nor distrust, but a "lack of clear expectations, as well as hesitation about committing oneself" (Sztompka, 1999, 26). Mistrust is often seen as something that corrodes social bonds. However, as Matthew Carey proposes, mistrust may also lead to social forms that are "interesting and occasionally admirable constructs in their own right" (Carey, 2017, 3).

Distrust, on the other hand, is a suspicious and cynical attitude, a settled belief of untrustworthiness (Lenard, 2008). It is saturated with antipathy and resentment, fear and anger (Jennings et al., 2021). Distrust is sometimes conceptualised as "the negative mirror-image of trust" which involves negative expectations about other people's

actions, and may lead to avoiding or distancing (Sztompka, 1999, 26). A person who mistrusts is sensitive to contextual changes and willing to be informed (Jennings et al., 2021). Someone who distrusts, in contrast, has their mind made up and may refuse new information. While mistrust describes a general sense that a person or thing is unreliable, distrust is more likely to be based on a specific past experience (Carey, 2017, 8). Losing trust in vaccination can then happen through a clearly definable experience or event (distrust), or via a gradually developing general attitude that certain people and institutions are unreliable (mistrust).

Instead of being fixed positions, discourses and practices related to biomedicine may show elements of trust, distrust and mistrust – a mixture of antipathy and respect (Leach and Fairhead, 2007, 31; Williams and Calnan, 1996, 1612). Trust, mistrust and distrust should not be seen as set attitudes or the mere psychological states of an individual. Analysis of how and why people do or do not trust vaccines should take into account that vaccination-related attitudes and perceptions are continuously being formed and reorganised. Because of this processual nature, people can move between different attitudes and their perceptions may incorporate elements of trust, distrust and mistrust toward vaccination.

3. Research materials and methods

While the broad narrative of eroding trust in vaccines or public health expertise is an insufficient analytical tool in understanding vaccine hesitancy, personal narratives of losing trust can provide detailed and contextualised insight into the processes of becoming vaccine-hesitant. Thus, our analysis is based on ethnographic interviews (Spradley, 1979) with 38 parents of partially-vaccinated or non-vaccinated children in Finland. These unique materials make it possible to delve deeper into the processes of losing trust in vaccination in the context of a high-trust society.

The first author recruited participants first by posting an invitation on an open Finnish vaccine-sceptic Facebook group. Later, more parents were reached through snowballing and through participants posting about the study on social media groups. Study participants thus included both individuals who were active in vaccine-sceptic (social media) networks and individuals who did not have many or any contacts in them. Even the participation of individuals reached through Facebook varied; some were active in discussions while others never joined in. We were thus able to reach both parents who were actively engaged with other vaccine hesitant parents and those who were rather isolated in their vaccine-hesitancy.

Socio-demographic information of participants can be found in Table 1. All participants had at least one child, and their children were between 2 months and 22 years old (most were minors). The participants had a total of 109 children, of which 46 were non-vaccinated, 38 were partially vaccinated, and 25 were fully vaccinated until at least the age of six. In conducting the study, we followed the guidelines of good scientific practice set by the Finnish Advisory Board on Research Integrity. All participants provided written informed consent. Participant names used in this article are pseudonyms.

Table 1
Socio-demographic information of participants.

	Number of participants
Female	35
Male	3
Age: under 35	12
Age: over 35	26
Education: high school or vocational school	16
Education: bachelor's or master's degree	22
Place of residence: city or large town	25
Place of residence: small town or rural	13

Almost all participants were female, which is understandable considering that women often carry more responsibility for health related decisions and practicalities such as taking children to their child health clinic check-ups. Many of the female participants said that they had gotten interested in vaccination, done most of the information seeking and then suggested to their possible spouse that they opt out of some or all vaccination for their child(ren). This is not to say that men were never active; several participants explained that their male spouses also looked into vaccination information and participated in the decision-making process. The three male participants were all actively involved in vaccine-related decision-making in the families, and two of them were more active than their spouses in information seeking.

The first author conducted the first set of interviews (N = 38) between 2016 and 2019. The author mostly visited participants in their homes, often meeting their families and having coffee or meals with them. The author made field notes describing these interactions before and after the recorded interviews. Although the participants mostly freely shared their stories about how they became vaccine-hesitant, all interviews covered three themes: 1) how participants started to question and eventually refuse (certain) childhood vaccinations, 2) which health-promoting and illness-preventing practices participants used, and 3) participants' experiences in the healthcare system.

In 2021, an invitation for another round of interviews was sent via e-mail to all 38 individuals who participated in the first set of interviews. Eight participants responded and were interviewed again by the first author to provide an update on their experiences during the COVID-19 pandemic. The second set of interviews were done over the phone, recorded and transcribed verbatim. After both rounds of interviews, many participants sent additional information they had forgotten to mention, or links to online materials such as articles, blog posts or videos. Two participants provided a written narrative of several pages, describing their "path to non-vaccination". In addition, instead of being interviewed again, three participants sent short written accounts (1–2 paragraphs) of their pandemic experiences in 2021. All of these materials, as well as field notes, were included in the analysis.

Previously reported findings based on the first set of interviews showed that the main reasons the parents gave for not vaccinating their children were 1) fear of adverse effects, or personal experience with (suspected) adverse effects after vaccination, 2) distrust towards actors and institutions involved in public vaccination policy, vaccine development, research and manufacturing, and 3) alternative health perceptions and practices aimed toward strengthening 'natural' immunity (Nurmi, 2021; Nurmi and Harman, 2022). In this article, we focus on the second point, starting with the empirical observation that all research participants had trusted vaccination in the past, at least to some extent. They had accepted recommended vaccinations for themselves, and often for their children. They had thought that the actors and institutions researching, developing and promoting vaccines could be trusted to act in the best interest of the public's health. The aim of our analysis is to provide an account of the *processes that lead from this position of trust to one of questioning, mistrust and distrust*.

Research materials were analysed using a narrative method (Riessman, 2008). First, a summary of each participant's narrative was compiled based on the interviews, field notes and possible additional materials supplied by the participants. Second, a timeline of each participant's process of losing trust in vaccination was composed. Third, we condensed the narratives into ideal types and created a typology that defined them in relation to the concepts of mistrust and distrust. Finally, the materials were read through again and participant narratives situated within the typology. Throughout the analysis, we have practiced an empathetic reading typical of ethnographic research, which facilitates

exploration of the participants' experiences and interpretations of the inner logic of vaccine-hesitant views.

In the next section, we present four ideal type narratives of losing trust in vaccines and share illustrations of each narrative: *the activist, the hesitant, the disillusioned* and *the negotiator*. After presenting the four ideal types, we discuss the significance of the typology in relation to previous research on vaccine hesitancy.

4. Four narratives of losing trust

Participants' narratives of how they came to lose trust in vaccination were typically characterised by either mistrust or distrust. We also observed that the dimension of certainty vs. uncertainty was pivotal in the narratives, especially in regards to temporality and living without trust in vaccination (see Table 2).

Narratives of mistrust can be described as a cyclical, gradual accumulation of knowledge, experiences, and understandings which eventually undermine trust in vaccination. The participants could not pinpoint a certain time or beginning for this process, which usually lasted several years. As is typical of mistrusting attitudes, participants were sensitive to and sought out new information, even if they felt their vaccination decisions were unlikely to change. We have distinguished two ideal type narratives of mistrust: the stories of the *activists*, who were fairly certain of their decisions, and the stories of the *hesitant* parents, who felt a deep uncertainty surrounding their vaccination decisions.

Narratives characterised by distrust, on the other hand, were more or less linear stories featuring certain events or experiences that had started the chain of events leading to the loss of trust in vaccination. Participants typically described these moments or events as 'waking up' or 'awakening'. Prior research has likewise identified 'awakening' or 'enlightenment' related to losing trust in vaccination (Hobson-West, 2007, 208), but has found that a search for information on vaccination happens before this 'awakening'. In our research materials, the emphasis was on the experience or event that shook participants' trust in vaccination and 'awakened' them into questioning that trust – which then lead to the search for information. We differentiate between two types of narratives of distrust: the *disillusioned* parents, whose trust had been irrevocably lost through an experience of sudden adverse effects from vaccination (usually in their children), and the *negotiators*, who suspected adverse effects but were less certain of their future vaccination decisions.

The narratives were also distinguished by different modes of temporality surrounding experiences of trust, distrust and mistrust. In narratives of mistrust, trust gave place to mistrust gradually, whereas in narratives of distrust, trust in vaccination was more abruptly replaced by distrust. Table 2 presents the four ideal type narratives in terms of the dimensions of mistrust vs. distrust, and certainty vs. uncertainty.

If participants were categorised in the narrative type that best correspond to their account, 18 parents' narratives would be characterised as activists, two as hesitant, four as disillusioned and six as negotiators. Despite this analytical separation, some of the participants shared aspects of two ideal type narratives in their accounts, one usually being more pronounced than the other. There was also a temporal aspect of moving between the narratives: for instance, many *activists* had gone through a phase of being *hesitant* and anxious about their vaccination decisions before acquiring a relative certainty. Participants may also have trusted certain vaccine-related actors, institutions or practices while simultaneously experiencing mistrust and/or distrust toward other vaccine-related actors or institutions. It is in fact typical of people to have a combination of different attitudes toward the same actors or institutions (Jennings et al., 2021).

Table 2
Typology of narratives of losing trust in vaccination.

	Mistrust	Distrust
Certain	*Activist*	*Disillusioned*
Uncertain	*Hesitant*	*Negotiator*

4.1. The activist

***The activist*s** were mostly parents of school aged or older children. Their path towards losing trust in vaccines had often started with an interest in healthy living. Some had encountered health problems and used complementary and alternative medicine (CAM) treatments in addition to biomedical treatments. Some had also studied CAM, either independently or through courses. Throughout these experiences, their attitudes of mistrust in public health experts and healthcare institutions grew stronger. At some point, some of the activists had witnessed adverse effects from vaccination. They had started reading about vaccination in medical publications or alternative health communities on social media. Having acquired knowledge about CAM and other alternative health practices, the risks of vaccination, and critiques of the pharmaceutical and health industry, they eventually felt confident enough to vaccinate their children selectively, or not at all. Many had started by postponing vaccination, and only later decided that they did not want to vaccinate at all. Trust in vaccination was thus lost gradually, and their attitudes reflected mistrust rather than distrust. These parents were often active in vaccine-hesitant and alternative health communities online, sharing content and supporting others. Some sought dialogue with public health experts, albeit with a mistrusting attitude, asking them questions about vaccination and challenging some of their views.

Example: Lena was a self-employed mother of two teenagers. Early on in her adult life, she had started reading about "*all things alternative*". How she had come to question and criticise vaccination was a bit of a mystery even to Lena herself. She had not really thought about vaccines before, but when she had her children in her forties, she thought she would hold off on vaccination until they were three years old, because vaccination seemed "*absurd*" to her. The more she read about vaccines, the more critical she became. At some point she realised that no one was going to take responsibility if something "*went wrong*" concerning the vaccination of her children – the responsibility would always be on the parents. Lena referred to her "*path to vaccine criticism*" as a long process during which she at some point realised that she was never going to vaccinate her children.

As Lena's children grew, they were very healthy and never needed biomedical care. Lena herself also avoided medications as much as possible. She had tried CAM treatments on occasion, but had not really needed them either. These experiences eventually made her very certain of her vaccination decisions. In 2016, Lena started to actively participate in social media discussions on vaccination. In her interview, Lena stressed that she was not a conspiracy theorist and that she believed that "*good people*" worked in the field of medical research. However, she believed that the money and power present in the pharmaceutical industry evidently have an effect on scientists, who are, after all, "*only human*". She heavily criticised the lack of placebo-controlled studies in vaccine research, emphasising that she did not want to dismiss science, only the dogmatic nature of scientific discussion when it came to vaccines.

4.2. The hesitant

Hesitant parents often started questioning vaccines after becoming parents. They had concerns about vaccine safety and did not feel comfortable vaccinating, but were not very sure they wanted to forgo vaccines altogether. They followed vaccine-sceptical discussions in social media groups, acquiring information but not participating in the discussions. The hesitant parents did not feel like they could understand medical research publications on vaccination, so while they kept looking for information, they mostly relied on others, such as members of vaccine-hesitant social media groups, to interpret this information.

However, they were also unsure about the extent these members could be trusted. Feeling like they could not really trust anyone – including themselves – to know the answers, they experienced anxiety regarding the vaccination of their young children. Relying on intuition, they postponed vaccines or selectively vaccinated. They often hid their children's vaccination status from friends and family because they feared judgement. Some of them faced pressure to vaccinate by healthcare workers, which increased their mistrust in the health system.

Example: Hanna lived alone with her daughter, who was a little under a year old. She had never had strong opinions on vaccines. When her baby was two months old, their public health nurse recommended the first vaccination according to the national schedule, and Hanna felt very worried about the potential side effects of the vaccine. Her baby seemed too little and immature to be vaccinated. She and her child's father decided that the baby did not need vaccination at that point.

Hanna didn't have much time to read medical research or other information, so she was mostly following her intuition in not vaccinating, and had not fully made up her mind. It felt very challenging to find impartial information. She doubted medical research on vaccines could provide conclusive evidence on vaccine safety because of study designs, and she also suspected that adverse effects from vaccination were concealed by health authorities so that people would not stop vaccinating their children. Making decisions felt very stressful, as she was worried about side effects as well as the possibility of her daughter contracting vaccine-preventable diseases. At the time of her interview, she and her baby's father had decided to wait until the child was at least three years old before vaccinating her.

Hanna did not know any other vaccine-hesitant parents. She followed some vaccine-critical Facebook groups, but had not interacted much with vaccine-hesitant parents on social media because she felt the discussions were often too confrontational. Hanna had not told her friends about not vaccinating her baby out of fear of judgement. At the child health clinic, their first nurse had strongly opposed Hanna's choice to delay vaccination, which prompted Hanna to change nurses. Hanna felt that the public discussion about vaccines was "*threatening and scary*", and that people judged non-vaccinating parents and labelled them as "*practically criminals*". She felt that as a single stay-at-home mother, she was already considered a "*lower-class citizen*" living on social welfare, and she feared accusations of free-riding herd immunity if people heard her child was unvaccinated. Hanna was worried that sanctions, such as loss of the universal child benefit, would be implemented against vaccine-refusing parents. She had even heard that criminal charges might be pressed against vaccine-refusing parents whose children contract vaccine-preventable disease. This all caused a great deal of anxiety and uncertainty about her vaccination choices.

4.3. The Disillusioned

Disillusioned parents had previously trusted vaccination and had complied with the recommended vaccination schedule. However, they had encountered an event that had caused a sudden crisis of trust. Typically, their child had a severe condition (such as narcolepsy or chronic fatigue syndrome) that was diagnosed by a medical doctor as an adverse effect of vaccination. Many of the disillusioned parents had fought for recognition and diagnosis of their children's condition. They had sought treatment mainly from the biomedical system, although some had complemented it with CAM treatments. They had also fought (sometimes in court) for social and financial support such as compensation or disability benefits. This double let down – first by the vaccinations that they trusted were safe, and then by institutions that they trusted to help if anything went wrong – had caused a sudden and sometimes complete loss of trust in vaccines, the public healthcare system, public health officials, and state institutions.

Some of the parents had acted or continued to act as caregivers for their (adult) child, having to take a leave of absence or quit their jobs. Some found support in peer groups on social media, meeting other parents whose children suffered from vaccine injury. A few had also started following medical research on vaccines. Most had either discontinued vaccination or started to vaccinate very selectively.

Example: Ida said she had never given vaccination much thought and had complied with the childhood vaccination program for her children up until 2009, when they got vaccinated with Pandemrix, the vaccine targeting the H1N1 influenza. In the following months, Ida and her three children got very ill, suffering from multiple neurological and general symptoms. Years later, they were finally diagnosed with conditions related to the Pandemrix vaccine. Despite diagnoses by several doctors in the fields of neurology and infectious diseases, nine years after the Pandemrix vaccination, Ida's family had still not received compensation. Her children eventually got better after treatments mostly given in the private healthcare sector, which Ida and her husband had to pay for. In 2021, Ida herself was still suffering from several debilitating symptoms but had not received disability pension despite multiple applications.

In her interview, Ida described her near total loss of trust in vaccination, public health authorities, the healthcare system, and public officials in general. This loss was precipitated by herself and her children getting ill after being vaccinated, as well as the way they were treated by the public healthcare and social insurance systems. In the beginning, she had thought this was just a case of "*one bad vaccine*", but over the years and after discussions with many doctors, she said she now viewed no vaccine as safe. Ida said that her children had also lost their trust in doctors. Her own view, based on her discussions with different doctors, was that the reasons she had not received compensation for vaccine injury or disability benefits were political rather than medical. She felt that her constant "*struggle with the authorities*" for compensation and disability benefits was part of a conscious strategy on the part of the authorities.

The COVID-19 pandemic exacerbated Ida's distrust of public health authorities, governmental and elected officials, and the political system as a whole. According to Ida, the pandemic turned Finland into a society with only one truth, in which all dissonance about vaccination was silenced. She felt certain that the media and public health authorities were lying to the public about the danger of COVID-19 and the safety of the vaccines. Notably, this had been her experience and that of many others who had suffered adverse effects and were left without state support after receiving the Pandemrix vaccine ten years prior. In her interview in late 2021, she said that she was astonished to learn that the Finnish parliament had approved the COVID-19 vaccination passport – which she felt was unconstitutional and against human rights. She said she was thinking of never voting again, because she had lost her belief in the whole political system.

4.4. The negotiators

The negotiators were parents who had previously followed the recommended vaccination schedule, until something "woke them up". Most often, their child(ren) started to experience symptoms that the parents suspected were caused by vaccination. This concern, however, was dismissed by healthcare workers, who assured the parents – often without really examining the child – that the symptoms could not be related to vaccination. Such dismissal, which sometimes included an experience of being ridiculed or labelled by doctors or nurses, damaged these parents' trust in the healthcare system and vaccinations. The parents then started to look for information on vaccines. They found other parents with similar experiences and started to question official statistics about vaccine side effects; if a group of people this large was possibly suffering from adverse effects, and their concerns had not been taken seriously, who knew how many cases were left out of the statistics? The negotiators started to feel distrust toward vaccine-related institutions, which led them to discontinue vaccination or selectively vaccinate. However, their vaccination decisions were often temporary in the sense that they did see (partial) vaccination as a possibility in the

future. Their current focus, however, was on getting their children healthy again, and this often led them to use both biomedical and CAM treatments.

Example: Anna's daughter was vaccinated against rota virus as a baby, and had diarrhoea for two months afterwards. Anna talked to a nurse about the diarrhoea several times, but the nurse did not confirm or report it as an adverse effect. At 15 months, Anna's daughter received the MMR vaccine. After that, she had blood in her stool for six months, but medical tests revealed no cause for this – however, she was diagnosed with an egg allergy. Later, Anna's daughter was diagnosed with severe asthma, which restricted the family's social life during flu seasons. Anna used a combination of diet, CAM treatments and biomedical treatments for her daughter's asthma and other family members' seasonal colds.

Anna had heard about cases of adverse effects from vaccines from her employer (a CAM practitioner) and her acquaintances. Anna reasoned that the egg in the MMR vaccine may have caused her daughter (with her egg allergy) to have a leaky gut, which then set off the asthma. Medical doctors told her that the asthma could not be linked to the vaccine, and that her daughter would have asthma even if she hadn't been vaccinated. Anna questioned this, because no one in their extended family had asthma. When Anna's second child was born, she and her husband (who, Anna said, was even more hesitant about vaccines than she was) opted out of most recommended vaccines for the baby. Still, they were "*too afraid*" to refuse all of them, and decide to take the DTaP-IPV-Hib combination vaccine to protect the baby from what they felt were the most dangerous diseases. Though she kept worrying about vaccine-preventable illnesses, she feared adverse effects even more.

5. Discussion

Throughout their narratives, participants described an ethos of mistrust. Instead of "blindly" trusting the biomedical health system, it was crucial for them to critically examine its recommendations, knowledge production and practices. Mistrust thus acted as a constructive force within vaccine-hesitant groups (see also Hobson-West, 2007, 208). In this manner, mistrust contributed to a "philosophy of rugged autonomy and moral equality" that perceives other people as "both free and fundamentally uncontrollable" (Carey, 2017, 10). Previous research has shown that distrust in medical professionals creates "firm boundaries between in-groups and out-groups" and that while "self-diagnosing empowers the community and affirms its boundaries, building credibility strengthens the community, [and] advocacy grows it." (Duchsherer et al., 2020, 428). However, the situation was more complex in our materials, as many participants felt they should not even trust the leading vaccine-sceptics, but examine all information with the same level of questioning. Trust was thus not transferred from public health institutions to vaccine-sceptic actors, but rather replaced by the ethos of mistrust. This demand to trust one's own judgement in evaluating relevant information was a unifying theme in the four types of narratives of losing trust.

Previous research on vaccine hesitancy has likewise documented that passively trusting the officials is seen as risky, whereas mistrust and taking personal responsibility empowers (Hobson-West, 2007). This insistence on trusting oneself as an expert in the health of one's children has been described as characteristic of the neoliberal ethos in intensive parenting practices, mostly encountered in privileged settings (Carrion, 2018; Duchsherer et al., 2020; Hobson-West, 2007; Lupton, 1995; Reich, 2014). Some participants in our study were confident that they could make the right vaccination choices for their children, while others were struggling with self-doubt. While everyone felt this ethos of "rugged autonomy" (Carey, 2017, 10), not all parents had equal possibilities to respond to these moral demands of personal expertise. Differences in education, income level, and job status translated into some participants having more time, energy and capabilities to seek information and to feel more confident in the level of personal expertise they had reached. Difficulty fulfilling this normative expectation caused considerable indecisiveness and worry in some participants.

Another unifying thread in parents' narratives was concern about the influence of the pharmaceutical industry through lobbying, as well as possible corruption among public health and governmental authorities. This can be linked to broader critiques of (pharmaceutical) capitalism, the blurring of the private and public sectors in biomedical research (which can affect public trust in science, see Chalmers and Nicol, 2004), and the privatisation or capitalisation of health. Similar concerns about the commercialisation of biomedical research and the involvement of the pharmaceutical industry have also been reported in Finland in relation to biobanking (Snell et al., 2012). The COVID-19 pandemic made these concerns more visible in mainstream discussion, and as such, the unprecedented profits made by certain pharmaceutical companies from the sale of mRNA-vaccines, as well as patent protections and the resulting vaccination gap between the Global North and The Global South, were discussed in the media. The possible problematics of public vs. private funding of research and collaboration between public officials and the medical/pharmaceutical industry is, of course, not limited to the research and development of vaccines, but is present in all medical research and has also been discussed within biomedicine and the field of science studies (e.g. Sismondo, 2018).

While ties between the pharmaceutical industry and public health authorities need not be indicative of corruption, they can be problematic in terms of trust between the publics and the health authorities. Collaboration between industry and public authorities clearly creates mistrust in some citizens toward public health officials as well as toward the entire chain of knowledge production and distribution concerning vaccines. Mistrust or distrust toward national vaccine-advocating institutions is also strongly affected by the historical context of (mis)trust between state and citizens (see e.g. Pop, 2016). 'Broken promises' from authorities increase mistrust in vaccination (Ward and Coates, 2006). In Finland, the recurrent theme in parents' narratives was the cultural memory of the N1H1 ('swine flu') pandemic in 2009–2010, during which a vaccine procured from the pharmaceutical company GSK (with which the Finnish National Institute for Health and Welfare had research collaboration) caused cases of narcolepsy, especially in children and young people.

The COVID-19 pandemic was an important event that can affect the experience of not trusting vaccination. In the interviews conducted for this study in the fall of 2021, some participants voiced increasing experiences of marginalisation, mistrust and distrust. They felt that public discussion about vaccination had become much more polarised during the pandemic. Like Ida (see section on the *disillusioned* narrative), they described a loss of trust that extended beyond vaccination or healthcare systems to include the government and the mainstream media. These experiences resulted in some of the participants turning to conspiracy theories to make sense of what was happening, while others felt stuck between mainstream vaccination views and the radical conspiracy theories, receiving little support or understanding from either side. This latter group described a mainstream "*culture of pressuring and intimidation*" (Leo) that pushed vaccines as the only solution to the pandemic and was quick to label anyone who questioned vaccination as a conspiracy theorist. In this sense, the polarised public debate on COVID-19 vaccines had the tendency to push many previously vaccine-hesitant individuals further into the margins and hinder experiences of trust toward governmental and public health experts.

6. Conclusion

Theoretical discussions on trust, mistrust, and distrust have typically not profoundly informed empirical research on vaccine hesitancy. This research has often described trust and the lack thereof as essentially separate, opposite positions. In this article, we have shown how relying on the trust/mistrust/distrust -family of concepts can deepen our understanding of the processes of losing trust in vaccination. We have

examined how these processes lead individuals to abandon the dominant cultural narrative of vaccines as a safe and efficient tool in preventing disease (on the vaccine narrative, see Heller, 2008). While we have analytically separated the concepts of trust, mistrust and distrust, it is important to bear in mind that they manifest in an intertwined manner in attitudes, experiences and actions. Thus, vaccine-hesitant individuals can also experience trust in certain aspects of biomedical expertise, sometimes even certain vaccines.

As shown in our analysis, vaccine hesitancy develops in the intersections of personal experiences, social relations and social networks, encounters with healthcare institutions and governmental institutions, the media, public opinion, and public discussion. In terms of experiences of mistrust and distrust, we identified two distinct paths for losing trust in vaccination in the narratives of Finnish parents. One was connected to mistrust – a general suspicious attitude in relation to the pharmaceutical industry and the vaccines it produces. The other was associated with distrust, and portrays a more sudden loss of trust in authorities – critique was aimed primarily toward the actions of (public health) authorities or healthcare professionals, and only secondarily toward vaccines as products of the pharmaceutical industry.

Mistrusting type of vaccine hesitancy in particular manifests as pondering, information seeking and questioning that develops over the long-term. This leaves room for medical and public health institutions to support decision-making by engaging in respectful dialogue during healthcare encounters or by communicating that the publics' vaccination concerns and desires for transparency are being taken seriously.

Although the process of losing trust may be considerably faster in the distrusting type of vaccine hesitancy, it is possible for healthcare professionals and public health actors to at least partially repair the severed relationship. Taking suspicions of adverse effects from vaccines seriously in clinical encounters, and making sure that adequate medical, social and financial support is offered in cases of diagnosed serious adverse effects are two examples of how this could be achieved. Repairing this relationship is especially important, because personal narratives of unresponsive or disrespectful interaction on the part of vaccine-advocating institutions and their representatives, and a lack of support in cases of diagnosed adverse effects, are widely shared in social media, creating identification and communities around these experiences of distrust.

Our analysis offers further insight in showing that criticism and hesitancy take different forms within the dimensions of mistrust and distrust as well as certainty and uncertainty. Importantly, the narrative types identified in our analysis are not fixed positions, but can develop and change in the course of personal experiences, societal events and evolving public discussion. Individuals negotiate between different orientations and combine them creatively.

Our study has certain limitations. First, the COVID-19 pandemic may have impacted the processes of becoming vaccine-hesitant with 1) its heavy media coverage of the development of vaccines, including uncertainties related to the efficacy and safety of the vaccines, 2) heated debate over vaccine mandates and other COVID-19 policies, and 3) the polarisation of vaccine-related views. As most of our materials were gathered prior to the pandemic, we cannot analyse these possible shifts in this article. Our analysis does, however, offer a good point of comparison for the examination of possible pandemic-related changes. Second, the scope of this article and the materials used did not allow for analysis of the interplay of gender and ethnicity in how distrust and mistrust in health systems are formed (see Ward and Coates, 2006); this is also something further analysis should focus on.

Our results emphasise that building trustworthy health systems is not simply a question of training healthcare professionals to listen to and talk empathetically with patients. It requires the development of institutions that commit to the values of transparency, solidarity and fairness and can effectively and respectfully communicate these commitments to the critical publics. Especially during the polarised public discussions related to COVID-19 vaccines and public health policies, vaccine-hesitant and vaccine-refusing individuals were rebuked and ridiculed – sometimes by representatives of the institutions they were asked to trust in relation to vaccines. Through the processes of losing trust in vaccination, solidarity is directed away from the wider society and the idea of herd immunity, and turned toward communities of "mistreated others" (vaccine adverse effects peer support groups, groups promoting vaccine-scepticism or conspiracy theories) that are loosely held together by mutual attitudes of mistrust and experiences of marginalisation.

Currently, refusal to get vaccinated may result in social and state-inflicted sanctions, depending on country and profession (such as withdrawal of social benefits, denial of access to public day-care or schooling, and loss of work opportunities or salary). The COVID-19 pandemic showed that vaccine mandates and sanctions for non-vaccination can be successful in the sense that they result in some individuals reluctantly accepting vaccination in order to avoid sanctions. However, on the basis of our analysis, we underline that these kinds of vaccination policies do a disservice to efforts to build trust between people and governments or public health authorities. Eventually, they may also affect the credibility of scientific expertise and knowledge production.

Ethics approval

The guidelines of good scientific practice set by the Finnish Advisory Board on Research Integrity have been followed in conducting this study. No ethical review was required according to the guidelines of Ethics Committee for Human Sciences at the University of Turku.

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Individual contributions

Johanna Nurmi: Conceptualization (equal); writing – original draft preparation (lead); formal analysis (lead); methodology (lead); writing – review and editing (equal). Joni Jaakola: Conceptualization (equal); writing – original draft preparation (supporting); formal analysis (supporting); writing – review and editing (equal).

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The authors do not have permission to share data.

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