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Leaky bodies, vaccination and three layers of memory: bio-immune, social-collective and lived experience

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ABSTRACT

This paper focuses on the omnipresent yet analytically almost invisible role of memory and bodily experiences in childhood vaccination. Previous scholarship on the sociocultural aspects of vaccination has primarily focused on the individual and sociodemographic factors underpinning vaccine hesitancy, the role of healthcare professionals and the politicisation or mediatisation of vaccination. Social practices considering vaccination were primarily explored as a matter of the present. Only little consideration was given to the past, individual biographies and sociohistorical temporalities. To complement this body of work, we focus on cognitively-based, embodied and emotionally-experienced memory related to vaccination. Based on a qualitative study of childhood vaccination conducted in Czechia between 2017 and 2019 consisting of ethnographic observations, in-depth interviews and a document review, we identified three interconnected forms of vaccination memory: bio-immune, social-collective and lived experience. Bio-immune memory refers to the body's physical memory, gained to protect itself from diseases. Social-collective memory focuses on socially shared narratives about diseases and vaccination in the past. The memory of lived experience refers to feelings, embodied knowledge and pain. Our findings may inspire further analysis of childhood vaccination in other geographical contexts and amidst the reconfiguration of attitudes and newly established memories following the COVID-19 pandemic.

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Vaccination; leaky body; leakiness; memory; embodied memory

Introduction

When I was 11 years old, my classmates and I were getting a tuberculosis vaccine booster at school. I remember our teacher showed us a scar on her shoulder from the vaccination she received at the same age. She said there were times she didn't like the scar, but now she thinks it's rather pretty. Before the vaccination itself, we were tested for the presence of tuberculosis antibodies. The test was made on our forearms. My body's reaction – swelling – was big enough that the vaccination itself was unnecessary. I was thrilled, not because I was afraid of the scar but because of the fear of possible pain.

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This paper examines the role of memory and temporality in childhood vaccination. The above story is based on a diary entry by the first author of this paper and is particularly relevant to exploring the rather invisible and almost neglected role of memory in childhood vaccination. It anticipates our analysis in three ways. First, the story portrays the author's individual remembrance of her vaccination experience, including her feelings of fear and expectation of pain. Second, the story shows the highly embodied nature of the vaccination experience and, more specifically, how vaccination can be inscribed into bodies by leaving a scar, which also symbolises the collective experience shared across generations in Czechia. Third, the reference to antibodies is related to the body's physical, immunological memory of previous vaccination.

These three themes are observed within our ethnographic study, which explores the diverse ways in which parents, experts and stakeholders enact vaccination memory: through the individual memory of lived vaccination experience, the social-collective memory that transcends and connects individual and collective bodies and the body's bio-immune memory. We suggest that discourses, attitudes and actions concerning vaccination are not simply underpinned by cognitive and stable types of memories, confined to individual actors. Inspired by the work of Shildrick and her notion of 'leakiness' (see, e.g. Shildrick, 1997, 2019), we instead argue that they are highly embodied, unstable and leaky. Therefore, vaccination memory is imprinted in individual bodies, becoming, at the same time, collective bodies. Similar to Shildrick, we argue that both individual and collective bodies emerge in the process of becoming rather than remaining in a state of being, affected by different layers of cognitive, embodied and emotional memories. That said, leakiness here is understood in its close nexus with temporalities, transformations in time and memory.

The significance of memory and time in relation to vaccination has recently been reflected in several accounts of the COVID-19 pandemic and, more directly, to the vaccinations. The analysis of the public debate suggests a variability and fluidity of vaccine temporalities in public debates around vaccine development (see Harrison, Lancaster & Rhodes, 2022). Historical imagination and the memory of past epidemics framed the pandemic experience by constructing links between pandemics present, past and future (Battles & Sanders, 2022). Remembrance legislation, monuments and other commemoration artefacts introduced in a top-down manner by the state served as another example of the memory at play emerging in response to global pandemics (Vinitzky-Seroussi & Jalfim Maraschin, 2021).

In the analytical account that follows, we situate our discussion of memory and temporality in the pre-COVID-19 context. We draw from fieldwork investigating the politicisation of the Czech vaccination debate conducted between 2017 and 2019 to explore the meaning of memory in social practices and discourses related to vaccination. We locate our analytical focus on temporalities and embodied memory in existing accounts of debates concerning vaccination. We conclude by discussing the potential benefits of applying the concept of memory to the vaccination field.

Childhood vaccination, body and memory

Previous scholarship on the sociocultural aspects of vaccination primarily focused on the individual and sociodemographic factors underpinning vaccine hesitancy (e.g. Reich,

2014; Hasmanová Marhánková & Skálová, 2016), the declining trust in expert and public health authorities and biomedical knowledge (e.g. Goldenberg, 2021; Larson et al., 2018), the role of healthcare professionals (e.g. Deml et al,; 2022; Paterson et al., 2016), civic engagement and activism on the part of vaccine-hesitant parents (e.g. Hobson-West, 2007; Hasmanová Marhánková, 2014; Numerato et al., 2021) and the political instrumentalisation of vaccination (e.g. Lasco & Curato, 2019; Speed & Mannion, 2020) or its mediatisation (e.g. Sobo et al., 2016; Numerato et al., 2019). The primary focus of these accounts was on vaccine hesitancy. Some underlying factors identified in the literature included experiences, emotions and risk perceptions related to the risks of adverse vaccination effects or those of vaccine-preventable diseases (Dubé et al., 2018).

Existing literature has examined how memory served as an explanatory concept to analyse vaccine hesitancy in the post-socialist context, one similar to the Czech context analysed throughout this study. The post-socialist memory of the communist regime and, notably, the legal obligation to vaccinate – viewed as political oppression in opposition to freedom – can trigger unwillingness among parents to vaccinate their children (Bazylevych, 2011; Hasmanová Marhánková & Skálová, 2016; Trifunović, 2019). Memory has also re-entered vaccination scholarship amidst the COVID-19 pandemic, serving as a tool to understand the historical temporalities of vaccine development and public debates as well as the collective experience with vaccine-preventable diseases. The remembrance of the Spanish flu and polio epidemics as important historical touchstones worked as a tool to cope with the newly emerging uncertainties (Battles & Sanders, 2022). Narrativised accounts of the long history of vaccine development have also situated vaccines and vaccine decision-making within linear timelines of technoscientific progress (Harrison, Lancaster & Rhodes, 2022). Moreover, the memory of epidemics has been imprinted into the knowledge production process, notably as regards architecture and urban planning with their roles in the prevention and treatment of diseases, newly emerging public health policies and the scientific development of vaccines (Vinitzky-Seroussi & Jalfim Maraschin, 2021).

Social-collective memory practices include lacking, forgetting and recalling memories and have implications for the present and future (Berliner, 2005; Hodgkin & Radstone, 2003). Due to its interactional nature, memory can be selectively adopted and manipulated. Furthermore, consumers of cultural and intellectual traditions can 'ignore, or transform such [*memory*] artefacts according to their own interests' (Kansteiner, 2002, p. 180). From this perspective, collective memory is maintained by multiple processes, agendas and actors and 'our understanding of the past has strategic, political, and ethical consequences' linked to the present and the future (Hodgkin & Radstone, 2003, p. 1).

In addition to cognitively-framed forms of remembrance imprinted into shared stories and narratives, memory is also embodied (see also Narvaez, 2006). Through these lenses, Vinitzky-Seroussi and Jalfim Maraschin (2021), inspired by the work of Sturken (1997), suggest that the immune body represents 'a memorial, a technology that retains records of the body's activities and what has travelled through it' (Sturken, 1997, pp. 243–244), potentially fostering immunity. The concept of embodied memory begets an understanding of the body and, simultaneously, of the memory-building processes inscribed into the body. The embodied nature of memory has been well reflected in

the public and expert debates over the uncertainties concerning bodily immunity memory and, more specifically, in discussions about whether immunological memory exists as a specific capacity of the immune system to protect the body against infections and diseases (see, e.g. Zinkernagel, 2018).

This paper, which is informed by phenomenological epistemology, emphasises the role of the body and embodied memory in the context of vaccination. Building on Merleau-Ponty's (1962) notion of the pre-objective body and concurring that 'remembrance is the work of our body' (Szaló, 2017, p. 15), we argue, together with Fassin (2007), that within the body, as 'a past embodied in a present' (p. 177), collective processes and culture emerge.

Inspired by the work of Shildrick (1997, 2019) and her notion of leaky bodies, we can conceive of individual bodies as reciprocally interconnected. Shildrick argues that the body is more likely a constantly unfinished process rather than a coherent, complete and bounded entity. Its inherent changeability and leakiness consistently compromise bodily stability. The body is continuously becoming in sets of relations to other similarly unstable entities. The body stays dependent upon other bodies and never becomes fully autonomous.

In the same way that individual bodies are constantly emerging through leakiness, leakiness is also behind the constant emergence of the collectives of bodies. In other words, individual bodies are never fully separated from others and are constantly interacting with the external environment due to their leakiness (Shildrick, 1997). Hence, we argue that memory and its forms represent one of the vehicles through which this interaction takes place. The leakiness of memory shapes the memory work of individual bodies and the emergence of collectives of bodies bearing specific memory. Moreover, as Shildrick (2022) emphasised in her work on the COVID-19 pandemic, the leakiness of biological and social bodies expressed through the mutual dependence between community and immunity are intertwined processes that create an intertwined collective of bodies.

The notion of a leakiness that implies permeability leads us to simultaneously consider both individual biographies and sociohistorical temporalities, focusing on not only cognitively-based but also embodied and emotionally-experienced memories.

Methods

The paper draws on data generated between 2017 and 2019 in Czechia as part of the research project 'Civic Engagement and the Politics of Health Care'. The project primarily focused on the politicisation of healthcare, citizen engagement and health activism, including the focus on vaccination[1] as one of the two case studies.

Semi-structured interviews were conducted with members of Czech non-governmental organisations focusing on vaccination, vaccine-hesitant parents and health care professionals and experts involved in vaccine-related public debates. The sample included a vaccinologist, two immunologists, six other medical experts (e.g. a paediatrician, two pharmacists, a physician and two homoeopaths), a biologist, seven members of Czech non-governmental organisations (including six parents), a public health expert, a medical journalist, an infectious disease specialist, a lawyer and an artist ($N = 23$). Further data were generated through observations at meetings, protest rallies, seminars

and conferences; from online documents such as websites, policy and legal documents, meeting minutes and blogs; newspapers, including newspaper interviews; documentary films and video recordings of seminars and conferences; and autoethnographic fieldnotes. Given the inevitable difficulties in accessing the hidden and vulnerable communities of parents who are vaccine-hesitant or critical of vaccination (see Hilário et al., 2023), snowball and convenience sampling techniques were used to increase the heterogeneity of participants and documents as well as to achieve data and conceptual depth saturation (see Nelson, 2017).

The participants were identified thanks to the above-mentioned review of available documents concerning the childhood vaccination debate in Czechia. Participants were approached based on their engagement in the public Czech vaccination debate, with an effort to include participants with diverse positions and roles. The relevant events and venues for observation were identified via the fieldwork, interviews, communication with participants and the abovementioned document review.

The analysis was conducted partially both in NVivo and manually and was inspired by some principles of coding developed as part of grounded theory, more specifically, by open, selective and axial coding (see Corbin & Strauss, 1990). As anticipated above, the focus on memory and embodiment emerged as part of the open coding process. The topics related to embodiment and memory emerged as important aspects underpinning the vaccine hesitancy debate. These interim observations increased our sensitivity towards both memory and the embodied nature of vaccination and, at the same time, determined the selective coding process used in the initial stage of the analytical process. Finally, the axial coding helped to explore the relationship between the different codes and, particularly, the creation of the categories of bio-immune memory, social-collective memory and memory of lived experience. Quotations from the interviews were anonymised and appear in the paper translated by the authors from Czech to English.

The research ethics were built upon the ethical principles of the Code of Ethics for Researchers and was approved by the funding agency, the Czech Science Foundation (GAČR). The interviews were conducted with informed consent. A draft of the paper was sent to the quoted interview participants for authorisation.

Findings

As part of our analysis, we identified three forms of memory linked to vaccination: bio-immune, social-collective and the memory of lived experience. First, *bio-immune memory* refers to mnemonic processes in the body at the biological and immunological levels and, more specifically, to the effectiveness of the individual or collective bodily immunity fostered either by vaccination or by an encounter with a vaccine-preventable disease. Second, the notion of *social-collective memory* refers to the often intertwined individual, personal, family and cultural memories of vaccine-preventable diseases and their impacts; stories about the side effects of vaccination; and the narratives about the success of vaccination. The last, third type is the phenomenological *memory of lived experience*, which recollects moments of bodily experience and perceptions of the world. It emphasises the influence of feelings and pain on understanding vaccination.

Bio-Immune memory

All research participants addressed bio-immune memory in the interviews. They related to the bio-immune memory by describing how vaccination works (or fails) in the immune system. Their conclusions about vaccination differed significantly. However, these accounts connect with the three memory stimuli (vaccination, experience with a disease and circulation of a virus within the population) and bio-immune memory leakiness.

From an immunological perspective, the spread of infection among bodies highlights the permeability of bodily boundaries. This leakiness is also a fundamental condition for establishing herd immunity. Herd immunity is created when a large percentage of the population is vaccinated, thereby interrupting the spread of infection between the vaccinated bodies and reducing the risk of infection for unvaccinated individuals (Chlíbek et al., 2010). An immunologist participating in the research illustrated herd immunity and the spreading of disease on specific leakiness regimes between protected (vaccinated) and unprotected (unvaccinated) bodies:

> If we did not vaccinate 4, let's say 5 per cent of people, it would be all right. The other vaccinated people would epidemiologically handle it and protect them. A barrier would be erected; the infection would spread only locally and wouldn't go through to other bodies. For example, a case of diphtheria in Spain ended with one unvaccinated boy's death, and the disease was found in another six vaccinated kids. Although the antibodies in their bodies were proven – therefore the infection got into the body – because they were vaccinated, the disease did not fully develop, and they did not spread it. So basically, the classmates made a barrier around the unvaccinated one. This barrier prevented someone else's infection, for example, in the next school, the next classroom. (immunologist B, male, interview, September 2018)

As the previous quote suggests, if protected bodies surround vulnerable bodies, the bodies share the immunity and, simultaneously, create a boundary that the infection cannot cross. Therefore, vaccination establishes the *leakiness* of immunity and the *unleakiness* of infection and disease. To gain herd immunity, first, the population must contain a certain level of protected bodies, and, secondly, the vulnerable (unprotected) bodies must be dispersed in the population. The description demonstrates how the vaccinated bodies are *protected* from infection (or protected from the most severe effects of the disease) and how they *protect* other bodies. In the specific example mentioned by the immunologist who described this '*success of herd immunity*', only the first infected child died. However, the spread of the disease was further stopped thanks to the barrier created by other vaccinated classmates.

In addition to collective herd immunity, the *leakiness* of immunity concerns a more localised level of shared immunity between specific bodies, operating through a different biological mechanism. Another immunologist described pregnancy as immunity's leakiness, where a mother's body can protect her child based on her bio-immune memory:

> Passive vaccination protects us as well. It is passive in the sense that antibodies protect against infection. I would not apply antibodies directly to a child – I would not take them from donors and inject them directly into a child – but in the third trimester, the mother can be vaccinated. […] She would create the antibodies, which are transferred through the placenta, and the baby is born with protection for the most critical, vulnerable

> period of his or her life. Then, we can start to immunise actively. (immunologist A, male, interview, October 2018)

In the case of leakiness between the body of the mother and the unborn child (or, further, in the case of the infant), leakiness no longer occurs only in the context of leaky boundaries but emerges as a process that forms a newly formed and unique collective of bodies (mother and child/children), representing in a sense an example of the maternal corporeal generosity and gifting (Hird, 2007). In addition to the leakiness, the quotation shows the temporality of memory and, in particular, the problem of losing and refreshing the bio-immune memory. Firstly, a child will not remember the 'passive' immunisation for long, thus, must be protected with 'active' memory in the future. Secondly, for the mother, vaccination in pregnancy represents a reminder of 'what she had before' (immunologist A, male, interview October 2018) – bio-immune memory based on vaccination in her childhood.

Bio-immune memory loss affects vaccination strategies. For example, some vaccine-hesitant parents indicated that they may prefer to postpone selected vaccines for their children (e.g. against mumps) until an older age than is recommended by the vaccination schedule[2] as they believe that this fosters the vaccination's efficiency (bio-immune memory). More specifically, as the mumps example suggests, they would welcome postponing vaccination to an age when the disease can have more severe consequences (e.g. adolescence). Moreover, vaccine-hesitant parents often mentioned that 'vaccines fade over time' to argue that diseases could spread because of memory loss among adult bodies, and therefore, blaming unvaccinated children for epidemics is unjust.

> It took me several years before I realised that the kids are used for manipulation, saying that they would infect other children. […] I had not realised that the collective health debate is not about the children, that the children should be protected by adults that are not controlled. (artist, female, interview, December 2017)

In the above quotation, the artist (who is also a parent) argues that the public debate about herd immunity focuses on children without concerning adults, whose immunity is not monitored. This statement that adults 'are not controlled' illustrates the argument that the possible lack of vaccination memory among adults could represent untraced and uncontrolled immunologic risk (more significant than unvaccinated children). Through our analytical lenses, the instability of memory leads some actors to question whether (and under what conditions) bio-immune memory through leakiness creates a collective of bodies (protected against disease) at all, as well as what its immune limits are (especially related to its longevity). In other words, according to these research participants, bio-immune *forgetting* matters and the loss of bio-immune memory undermines herd immunity.

However, this position was not shared unanimously; some actors pointed out that herd immunity functions even irrespective of the loss of bio-immune memory, as is demonstrated by the following quote.

> [I]t does not mean that people who have been vaccinated as children stay immune for the rest of their lives. […] Even if there is a very low level of antibodies [after vaccination], when the level of herd immunity is high, it means that clinical cases of infection do not occur. Society is protected as a whole. This is the meaning of nationwide vaccination. (infectious disease specialist, female, radio interview, April 2018)

Despite vaccinations fading, the infectious disease specialist claimed that herd immunity still protects the population from outbreaks of clinical cases of infection. Even if individual bodies lose their bio-immune memory, the population's bodies collectively remember enough to stay protected.

Other participant accounts highlighted the importance of refreshing bio-immune memory through booster (re)vaccination practices. For example, one vaccinologist claimed that booster vaccination is necessary for the elderly because life expectancy has increased and 'some of the vaccinations cannot protect a person until the age of 70' (vaccinologist A, interview, November 2018). All the research participants, regardless of their position towards vaccination, and including citizens, medical professionals and experts, tended to agree that the bio-immune memory of the majority of vaccinations 'fades over time'. Nevertheless, participants referenced different timeframes for memory maintenance, used different terminology (e.g. 'vaccination efficiency'), and supported different (sometimes even opposite) strategies concerning memory loss.

The presence of a virus represents another discussed stimulus of bio-immune memory, significantly affecting the processes of forgetting and remembering. As the following quotation suggests, bio-immune memory could be lost together with the erasure of a virus from society.

> Immunity weakens because it does not meet the natural impulses. In Czechia, we practically eradicated measles, and people who are 35 years old have never met the wild type of measles virus in their life. In the past, the virus circulated around people that were vaccinated in their childhood, and every encounter with the virus meant boosting immunity. (vaccinologist B, male, newspaper interview, August 2018)

This vaccinologist suggested how vaccination's success and the virus's disappearance could have paradoxically led to the 2019 measles outbreak. Bio-immune memory from vaccination is time-limited, and the circulation of the virus in society participates in memory renewal. The virus represents a catalyst for the body to recall the protection and avoid memory loss. Several vaccine-hesitant actors pointed out the effect of the virus as well. In addition, they illustrated this effect with the memory of different generations.

> Our grandmothers and grandfathers almost all had measles. Then vaccination started. My parents did not get measles anymore because they were vaccinated. However, they still encountered the pathogen in society, […] the virus still circulated. This is a natural booster, a natural activation of the immune system. […] And a natural booster means that if we meet the pathogen, the disease, it refreshes our memory. […] The problem is that we do not meet the virus in society anymore. (parent A, female, interview, December 2017)

> Disease incidence is mainly caused by the gradual extinction of generations that were naturally immune. (medical expert, female, interview April 2018)

These two quotations create a picture of how bio-immune memories based on disease experience and vaccination are entangled with virus circulation. Each generation represents bodies with different features of bio-immune memory. The second quotation implies that herd immunity of the whole population starts to fail without the bodies of earlier generations, which have the long-term memory and protection built from disease experience. The statements of participants suggest that all research participants,

regardless of their position towards vaccination, (more or less) agreed that bodies do not tend to lose memory based on disease experience quickly, commonly and explicitly using the term 'memory'. However, opinions differed on whether getting infected is worth it, depending on the perceived degree of risk of the vaccine-preventable disease and on the stance towards vaccination more broadly.

> Of course, after having diseases, long-term immunity or even lifelong immunity can be created. However, there can be a complication during the illness. […] It is a kind of Russian roulette. (paediatrician, female, newspapers interview November 2013)

> I try to find a source of mumps to get my children the infection experience. I know about the disease, how to treat the symptoms and pass through it smoothly. I am not scared of it. (parent B, female, fieldnotes September 2017)

In the first quotation, the paediatrician states that creating a bio-immune memory of the disease experience is too risky because of possible complications. However, as the second quotation suggests, some parents were not scared of the complications and actively try to infect their children. Parent participants claimed that they sometimes prefered diseases over vaccination because they did not consider specific diseases as high-risk. In these cases, parents tried to provide the child with long-term protection by facilitating the child catching the disease, which they believed would avoid the potentially greater risks associated with the child becoming infected at an older age. Therefore, even this strategy is fundamentally related to the understanding of bio-immune memory. Whereas bio-immune memory is reinforced by stimulating virus transmission through disease as the main stimulus of immunity-building, the importance of vaccination is marginalised.

Social-Collective memory

The leakiness of social-collective memory is present in its relation to individual, personal, family and cultural memories. Collective memory and the personal memory of individuals are intertwined. Individual memories tend to be recalled and framed in relation to collective memories (Halbwachs, 1980). Personal stories can be employed to support collective memory or, on the contrary, to challenge it. The leakiness of social-collective memory creates an interpersonal memory world where individual and collective memories affect each other constantly (Kleinman & Kleinman, 1994), and where collective memories do not relate to narratives only but, at the same time, to collective bodies.

One interviewed journalist regularly worked with her family's narrative, telling her grandmother's story. In the example below, she recounted this personal story, pointing out that people who witnessed and experienced the diseases tended to be grateful for the vaccination and support it. Experiencing and witnessing the disease form the bio-immune memory and occur as an essential element of the social-collective memory.

> My grandma had diphtheria, and that means that she was damn lucky, because this is an infection that still causes death today. […] So, when she grew up, had children and these children could be vaccinated, it meant for her, 'I have the chance that my kids will not have to experience the same thing I did'. Today, we are in a situation where our parents did not have diphtheria, we did not have it, and when we have our children, then we perceive diphtheria as something historical, and it is a little bit weird to vaccinate against it, so we do not focus on it. (journalist, female, interview, September 2018)

The story shows the leakiness of social-collective memory – how personal experience becomes a family and social narrative that forms an understanding of the past and supports current practices. The grandmother's body becomes part of a collective of bodies carrying social-collective memory (of the dangers of disease, the commonness of death and the benefits of vaccination).

The commonly used phrase 'vaccination is a victim of its own success' refers to forgetting the disease's risks and the absence of disease experience due to vaccination. Vaccination supporters often identified this lack of social-collective memory as the primary source of vaccination criticism. The journalist above described this development through personal family history. In this story, different generations were the bearers of various bio-immune memory; the earlier generation bears the socially shared collective memory, which gets lost with each generation.

Other (vaccine-hesitant) participants openly disputed the dominant social-collective memory of vaccination success. They claimed that the merits of vaccination were overrated; that other factors (such as better dietary and sanitary conditions) fundamentally contributed to disease decrease – 'what helped these infections not be here anymore has not been correctly evaluated' (parent B, female, interview, November 2017) – and that 'the diseases were declining a long time before vaccination' (medical expert, male, interview, April 2018). Thus, they tended to refer to vaccination success stories as a myth that 'history does not support' (parent B, female, interview, November 2017). They offered alternative narratives of disease decline to replace the dominant social-collective memories and their implications for current vaccination practices.

The interactive character, described by Kansteiner (2002; see above), is fundamental to social-collective memory. The research participants often reacted to others' perceptions of social-collective memory. On the one hand, as the quotes in the previous paragraph suggest, vaccine-hesitant parents tended to contest vaccination success (as stated by vaccination supporters). On the other hand, the proponents of vaccination tended to interpret vaccination criticism as a lack of social-collective memory of diseases. Each contested the others' interpretation of the social-collective memory as well as their vaccination strategies.

Memory of lived experience

The memory of lived experience encompasses the diversity of feelings, embodied knowledge and inward experience of pain or suffering. For example, parents and doctors can experience the vaccination of their bodies and that of their children, the vaccination's side effects, suffering related to vaccine-preventable diseases, treatment of others' diseases or the vaccination of others. Feelings, experiences and knowledge do not remain confined within individual bodies; they tend to leak, move across bodies and further contribute to the process of bodies becoming (see Shildrick, 2019). The memory of lived experience is unstable and subject to transformations over time. Due to this instability, participants can reconsider their previous experiences and start relating to them in different ways. Some research participants, for example, started to think differently about their vaccination and health conditions after a long time period.

> I realised the connection between my health problems and vaccination many years later. When I was dealing with vaccination for my daughter during pregnancy, and I was

> reading vaccine package leaflets, listening to lectures, I found all my conditions listed in the package leaflet of a vaccine against hepatitis B, and then I realised the time matched. (Czech Associations of Patients, 2015, p. 86)

The quotation shows the mother was brought to reinterpret her health and illness experience by focusing on her daughter's health care. This example also suggests the selectiveness of experience's understanding, also observed in the case of socio-collective memory. Not everyone would understand the illness experience the same after reading package leaflets. Memory selectiveness is influenced by actors' perceptions of and attitudes towards vaccination. In other words, these perceptions and attitudes affect if and how different actors engage in the memory work and, therefore, inevitably influence how memory leaks. The generally leaky nature of the memory of lived experience is apparent when research participants tend to describe lived experiences connected to the bodies of others. As Mol and Law demonstrate, people can *feel* the physical states of others (2004: 52-55), which can shape their own vaccination (and disease) experiences and perceptions.

> It is very difficult […] because we have seen the negative side of vaccination. It means that sometimes doctors tell us, 'You have to vaccinate 'cause … I have seen a child die from this, and you haven't'. But they [doctors] see this negative part […], and I just see the repression's negative aspects. So, I guess I am, maybe partly, affected by that. I see the negative aspects of repression. (parent A, female, interview, December 2017)

This quote illustrates how meeting and working with people experiencing vaccination side effects and parents facing sanctions *affects* them. The parent, a member of an association of vaccine-hesitant parents, described how she was affected by helping parents whose children had complications after vaccination. She highlighted cases where medical authorities did not consider the complications as vaccination side effects, and the parents faced sanctions if they did not vaccinate their children again. The participant compared her experience with these parents to the doctor who witnesses a child dying from disease, saying that she understands the doctors' perspectives; however, her experiences with parents affected her as well.

Moreover, the leakiness of the diversity of perspectives and memories of lived experiences is fundamentally connected to how the vaccination experience of others influences the understanding of vaccination and vaccination strategies. Based on this influence, the Czech Constitutional Court recognised conscientious objections as an exemption from the obligation to vaccinate. The trial decision's central argument was that one of the parents worked with children with autistic spectrum disorders and believed that these disorders could be connected to vaccination. The court decided to favour the parents who refused to vaccinate their child because of the long-term negative experience with the side effects of vaccination.[3]

The leakiness of memory is possible across all kinds of bodies. However, parents tended to describe their experience of the physical states of their children's bodies in a particularly strong way, in a sense reflecting the unique regimes of leakiness. The Czech Associations of Patients (together with a group of parents) published a text titled *How the Vaccination System Intervened in Some Families' Lives* (Czech Associations of Patients, 2015). The book is composed of vaccination stories written by parents. The following extracts from two stories point out how mothers describe their feelings about the side effects of vaccination on children:

> I'll never forget it. My son could not be calmed down. At one point, he could not even breathe, and I just cried with him. (Czech Associations of Patients, 2015, p. 42)

> Today, after more than a year, I still have tears in my eyes when I remember what my daughter had to experience. (49)

These accounts show how parents can experience a child's pain, how vivid a child's bodily experience is for a parent and how it shapes their memories. They write about the pain felt as their children suffered and how the pain created an unforgettable memory.

Interaction with healthcare professionals can further represent the intensive lived experience affecting long-term vaccination strategies. Hasmanová Marhánková (2014) argues several parents decided to reject vaccination after experience with paediatricians who immediately, without doubts, excluded the possible connection of their children's condition with the vaccination or downplayed the condition as nothing serious. These observations are specifically relevant to the Czech post-socialist context and its frequent performance of paternalistic medical authority, leaving little space to mitigate the 'unpleasant vaccination experience' (comp. Elverdam, 2011) to which some research participants still refer when criticizing the current vaccination system in Czechia, speaking about 'a relic of communism that has no place in a democratic and free society' (parent C, female, interview, March 2018).

Finally, the memory of lived experience does not remain the exclusive domain of parents. Medical experts (and other vaccination supporters) repeatedly referred to feelings and emotions at conferences and seminars. In addition to the use of expertise, statistics, tables and graphs, they commonly referred to stories about vaccine-preventable diseases, often with photographic material; for example, photographs of iron lungs (a ventilator that helps patients breathe) were typically used to illustrate and emphasise polio's danger and to imply the importance of vaccination (e.g. expert conference and seminar; fieldnotes from June and October 2018). These observations resonate with the existing literature and the accounts of healthcare professionals who build their practices on their experiences and can rely on their 'instinct' and 'judgement', especially in times of uncertainty (Harrison et al., 2023).

Conclusions

With this work, we explore the role of the past, individual biographies and sociohistorical temporalities in the debates concerning vaccination. By focusing on embodied and emotionally- and cognitively-experienced memory related to vaccination, we have concluded that the myriad factors influencing the approach towards vaccination are underpinned by the many ways in which the diverse actors enact temporalities and memory. We identified and discussed three forms of memory linked to vaccination: bio-immune, social-collective and the memory of lived experience. These forms of memory are related, interconnected and partially convertible.

Our conclusions resonate with previous scholarship elaborated outside the context of childhood vaccination or vaccination more broadly. The notion of bio-immune memory reflects the call to consider embodied memory (e.g. Fassin, 2007; Sturken, 1997; Vinitzky-Seroussi & Jalfim Maraschin, 2021) and, notably, the debates about immunological

memory (e.g. Zinkernagel, 2018) built through vaccinations or encounters with a vaccine-preventable disease. The sociohistorical nature of temporalities refers to the constant interplay between social and individual memories (see e.g. Narvaez, 2006; Kleinman & Kleinman, 1994) emerging in the public debates as parts of interactions among actors with different positions towards vaccination who selectively share and use vaccination-related narratives and stories. Inspired by Shildrick (1997, 2019), we further argue that it is thanks to leakiness that individual and collective memories are shared. Leakiness is also constantly shaping the memory of individual becoming bodies in the context of the simultaneous emergence and permeability of collectives of bodies with their specific memories. Memory resides in bodies and, at the same time, moves and changes between bodies and their permeable boundaries.

The focus on leakiness, thus, allowed us to understand the porousness of individual and collective bodies in light of the mutual dependence between immunity and community (Shildrick, 2022). Similar to this mutual dependence, we can hardly disconnect the dependence of cognitive and embodied memories. The way in which memory operates is reflective; various forms of memory re-enter the world they reflect. The social networks composed out of porous individual and collective bodies not only contribute to building immunity but the cognitive narratives, as well as embodied feelings and lived experiences about these networks and the alleged function of vaccination in these processes, can also affect how such biological networks operate and therefore determine what is leaked.

Furthermore, the focus on temporality means that memory is unstable and exposed to selectiveness, new understandings and redefinitions (e.g. Kansteiner, 2002) affected by socio-cultural, historical and political contexts. Although all bodies can leak memory, its leakiness is enabled differently. Amidst a specific post-socialist context where criticism of the legal obligation to vaccinate has been viewed as a tool to strengthen freedom from a paternalistic state authority (Hasmanová Marhánková & Skálová, 2016), a diversity of memory-driven narratives occurred.

While this specific study is focused on the Czech context, our findings can inspire further explorations of memory work in different national contexts, as well as on the transnational scale. Further research on vaccination or other healthcare public debates must consider the interconnections of individual and socio-historical temporalities, often experienced and shared selectively. Moreover, with our focus on cognitive and embodied memories, we hope to inspire further research into the interplay between these two forms. The leaky nature of memory and the complex myriad of relationships between bio-immune memory, social-collective memory and the memory of lived experience must also be considered in further sociological as well as interdisciplinary research. Last but not least, future research could explore the role of social memory with the COVID-19 pandemic and, in particular, how the 'new' vaccine reconfigured attitudes towards childhood vaccination.

Notes

1. The vaccination system in Czechia is mandatory, and the vaccination schedule includes vaccines against nine diseases (diphtheria, tetanus, pertussis, poliomyelitis, Haemophilus influenzae type b, hepatitis B, measles, mumps and rubella). Parents failing this obligation can be fined up to CZK 10,000 (approximately EUR 385).

2. The vaccination schedule is governed at the national level by the National Immunisation Commission (i.e., the advisory body of the Ministry of Health).
3. Constitutional Court Judgment, Czechia I. ÚS 1253/14 (2015). https://www.usoud.cz/fileadmin/user_upload/Tiskova_mluvci/Publikovane_nalezy/2016/I._US_1253_14_an.pdf

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