A Shot at a Healthy Future
An extended case analysis of the turbulent beginning of HPV vaccination in Denmark

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In this article, we present an extended case analysis of the unruly reception of the HPV vaccine in Denmark. More specifically, we explore what happens to visions of a healthy future when high levels of social trust in a public vaccination programme are suddenly infused with uncertainty and doubt. Capturing the Danish public in 2013-2015, national news and social media platforms shared dramatic stories of young women confined to their beds following their HPV vaccinations. The Danish healthcare authorities reacted to this seemingly accelerating problem by setting up HPV clinics to care for the women. Simultaneously, HPV vaccination uptake plunged. Based on long-term ethnographic field research, we present the experiences of two main interlocutors, who both find them-selves in difficult situations and having to revise their visions of the future: Sophie, a young woman with suspected HPV vaccine side effects and Martin, a physician working in an HPV clinic. Overall, their accounts shed light on situations emerging during a challenging period in
the 2010s in which the Danish healthcare system was adjusting to a new information and media landscape. We show that the promise of a healthy future – sustained by welfare and vaccine technologies – is indeed a communal venture that is vulnerable to suspension and even collapse. When sufferings (such as pain or fatigue) were publicly paired and un-paired with the vaccine, it generated and sustained pervasive uncertainties and painful feelings of being doubted by others – reflecting and highlighting inherent tensions of preventative medicine and the Danish welfare society, including the subtle acts of power and resistance that occur within it.

Introduction: Visioning healthy futures with vaccines

The HPV vaccine – promisingly named »a public health breakthrough« – protects against strains of human papillomavirus that may cause cervical cancer. In 2009, the Danish government included the HPV vaccine in the Danish childhood vaccination programme for girls aged 12, and the majority of these girls accepted its terms and received the vaccination. The vaccine was furthermore made available through state-funded catch-up programmes to women born between 1985 and 1995, which resulted in a substantial increase in the number of HPV vaccinations received across Denmark. However, following these initial years of high uptake, the cohort-specific vaccine coverage dropped disturbingly from 80 per cent in 2012 (for girls born in 2000) to 32 per cent in 2015 (for girls born in 2003) (Statens Serum Institut 2017). Concurrently, there was a dramatic rise in reports of suspected side effects of the vaccine (Danish Medicines Agency 2019). Embodying these suspected side effects were several young women, who had their unsettling stories portrayed across national news and social media platforms. The young women reported experiences of widespread pain, frequent headaches, dizziness, fainting, fatigue and cognitive dysfunctions (Brinth et al. 2015a). In March 2015, a selection of these young women’s stories was broadcast on national television in a documentary called »The Vaccinated Girls«, bringing public attention to a climax. In response, the Danish healthcare authorities decided to set up HPV clinics to care for the women (Danish Regions 2015). Despite (or maybe because of) this prompt political action, the idea of a link between the HPV vaccine and the vaccinated women’s suffering was soon contested by scientific institutions, experts and stakeholders (Hammer et al. 2016). Before long, the outbreak of suspected HPV vaccine side effects became the object of media critique; and both social and legacy media ended up being blamed or self-reflectively taking the blame for caus-
ing moral panic and a decline in HPV vaccine coverage (Lynard 2018, Hansen & Mølbak & Hansen 2020).

On a global scale, declines in vaccine coverage over the last decades show that vaccination programmes are indeed fragile dispositions that rely not only on resources and infrastructure but also on people’s overall trust in vaccine technologies and belief in the healthy futures they promise (Hotez 2019). For a long time, vaccines have been praised as one of medicine’s most cost-effective measures, estimated to avert between two and three million deaths each year (World Health Organization 2020). As a particular healthcare technology, they target populations of healthy individuals and signify control of an uncertain future. As such, vaccines constitute a counterfactual healthcare technology as their benefits manifest through the absence of disease (Livingston et al. 2010:231). They are meant to reduce not only disease but also the risk of disease (Aronowitz 2010:27). Adding to this, the actual act of immunisation may cause the individual pain or discomfort, both in the short-term through skin perforation and in the long-term through side effects¹. Given the facts that vaccines are offered to healthy individuals and can cause side effects, trust in manufacturers and providers is integral to the practice of vaccination. Trust in fellow citizens being vaccinated is also a prerequisite for obtaining what epidemiologists call herd immunity². Hence, vaccination may be understood as a communal venture performed individually, which, in many ways, as we return to the Danish context, comprises the core vision of a social democratic welfare society that strives to secure social well-being and a healthy future for all. As noted by Danish sociologist Gøsta Esping-Andersen, the social democratic model of society constructs an essential universal solidarity, where “All benefit; all are dependent; and all will presumably feel obliged to pay” (Esping-Andersen 1990:28). As vaccines included in the Danish childhood vaccination programme are free of charge, people ‘pay’ with their participation, exposing themselves and their children to thoroughly calculated risks in order to secure the population benefits of improved health and economic growth.

In this article, we explore what happens to the vision of healthy futures when a vaccine programme is interrupted by a sudden lack of trust. Through an extended case analysis of the unruly reception of the HPV vaccine in Denmark, we examine how the high levels of social trust that usually characterise the Danish society (Svendsen, Svendsen & Graeff 2012; Larsen 2013) were translated into a care field (the HPV centres) and infused with uncertainty and doubt. Emphasising that the HPV vaccine is a specific technology imbued with the magical promise of an instant solution (Eco 2007) to cancer, we also investigate how it facilitated “a new
look into life” (Guattari 1993 in Escobar 1995:417). We study people’s experiences and expectations (Strzelecka 2013:265) and show how futures are at once imagined and shared in practice but also vulnerable to temporary suspension or even collapse, which is why revisions may be required. Our analysis is thus based on ethnographic material that gives us an insight into the fears and hopes of those who were the target group for the vaccine and those who worked at the front line of care during this challenging period.

Approaching healthy futures

The analysis presented in this article is based on ethnographic fieldwork conducted by the first author (Nielsen). In order to obtain detailed insights into the HPV vaccine programme and how it reconfigured into a policy and care field, Nielsen initiated fieldwork in two HPV clinics in 2016. Between 2017 and 2020, she extended the research into private clinics, focusing on integrated care, and research facilities, studying biomarkers of people experiencing suspected HPV vaccine side effects. She furthermore interviewed representatives of the Danish Health Authority, the Danish College of General Practitioners and the Danish Cancer Society and spent time in the private homes of women with suspected side effects. Interlocutors thus include healthcare specialists, researchers and women with suspected HPV vaccine side effects. In this article, we present the embodied experiences, expectations and encounters of two interlocutors. Tentatively inspired by the extended case method presented in Gluckman (2006 [1961]), which asserts the social as preeminently a matter of practice (Evens and Handelman 2006:3), our analysis emerges in and from empirical details.

We show how, in moments of national health controversy, embodied pains are silenced, futures are suspended and pasts are encouraged to be forgotten, leaving clinicians tightrope walking and frustrated and young women suffering while managing complex clinical limbos. More specifically, we introduce Sophie. Sophie is a young woman whose embodied experiences of joint and muscle pains restrict her everyday life and who, after years of healthcare seeking, feels dismissed by physicians and social relations due to her suspicion that the HPV vaccine caused her distress. We also present Martin. Martin is a passionate physician working in an HPV clinic whose motivation to care for his patients transforms into deep frustration when his patients fail to follow his advice of forgetting the past in order to envision a healthy future. While we do not mean to imply that
these two interlocutors form any representative totality, we argue that their accounts provide insights into how people and societies pursue a healthy future in practice. These insights constitute an important part of understanding the lives that are produced through controversy – controversy that will undoubtedly re-emerge. The following sections of this article thus hint at the experiential aspects of future building, both the bright and dark, which people share and do not share as well as the social processes that produce and shatter hope in practice – or that make practice temporarily hopeless.

**Weighing risks**

As mentioned above, the HPV vaccine protects against strains of HPV that may cause cervical cancer. These HPV strains are sexually transmitted and the vaccine therefore quickly earned a reputation as a “promiscuity vaccine” in the US (Gibbs 2006). As parental concerns centered on the vaccine inciting sexual risk taking (Vamos 2008), it did not take long before the HPV vaccine was promoted as a vaccine against cancer risk instead of sexual risk (Mamo et al. 2010, Colgrove 2010). This development added a new layer to the anti-vaccine movement in the US, where several political action committees work to deny children access to vaccines (Hotez 2019:332). In Canada, Connel and Hunt (2010) show that the national HPV vaccination campaign framed HPV and cervical cancer prevention as a “moral regulation project” that was directed at the regulation of the bodies of young girls (ibid.63). State and corporate framings of the HPV vaccine as a cancer vaccine specifically targeting young girls also spurred controversy in parts of Europe and in India (Stöckl 2010; Towghi 2013). Other challenges related to the complex process of implementing HPV vaccination programmes have been further examined in countries such as Austria and Japan (Hadolt and Gritsch 2017). Here, the authors argue that the marketing of the HPV vaccine is best understood as a dynamic process that may include sharp turns. In Austria, this was demonstrated by a policy shift towards state-subsidised HPV vaccination after years of withholding subsidisation due to public anxiety and the high cost of the vaccine (ibid.46-47). In Japan, it was demonstrated by the shift away from state support of the vaccine after reports of suspected side effects (ibid.53), side effects that were quite similar to the ones reported in Denmark, UK and Italy (Kinoshita et al. 2014; Gallagher 2015; Palmieri et al. 2017).
The idea of a causal link between vaccines and various forms of suffering (henceforth the vaccine/side effect pairing⁴) is not new. Perhaps the most well-known example is the suspicion that the combination measles-mumps-rubella (MMR) vaccine may cause autism, which was a viable concern among parents in the UK and elsewhere during the 1990s and early 2000s. Such pairings fuel cornerstone debates of our time, permeate widely into policy, professional, media and popular circles (Leach and Fairhead 2007:2), and augment a diffuse doubt and concern about vaccines in general (Kaufman 2010:9). As such, they demonstrate the contours of a contemporary “risk society” (Beck 1992, 2006), where health and health care are largely based on the idea of susceptibility, i.e. identifying and treating people in the present for conditions they are predicted to suffer from in the future (Rose 2007:18). Like risk thinking, the idea of susceptibility brings, as British sociologist Nikolas Rose writes, “potential futures into the present and tries to make them the subject of calculation and the object of remedial intervention” (ibid.19). The cultural penetration of vaccine/side effect pairings points to the limits of susceptibility in relation to vaccines because they are shown to carry their own risks of disease. It then becomes a question of weighing up the risks of the disease the vaccine promises to prevent against the risk of the potential side effects – both of which are undesirable futures.

In Denmark, the unruly reception of the HPV vaccine was not only unusual but also unparalleled. For years, it has seemed that the majority of Danes are willing to pay the price of vaccination (i.e. take the risk) since uptake of vaccinations in general has been relatively stable at approximately 80-90 per cent coverage (or higher for the vaccines included in the Danish childhood programme) (Statens Serum Institut 2020). Moreover, controversies related to vaccines, such as the longstanding concerns about the MMR vaccine causing autism, have had limited impact on vaccination uptake in Denmark (Berg 2020). In short, the futures that vaccines promise seem to be preferable to most Danes. Yet this was not the case with the HPV vaccine.

The local configuration

To begin to understand the Danish HPV vaccine controversy is to understand how it developed within a well-established vaccination programme in a society characterised by high levels of social trust and cohesion (Svendsen et al. 2012; Larsen 2013). Defined in terms of optimistic expectations to interaction outcomes
with others, thus pointing to future situations, and an underlying understanding of the functions of the social fabric of society, Svendsen and colleagues argue that social trust in Denmark is derived from two main factors: early state building combined with long periods of political stability (2012:352,363). This is further reflected in the development of the universal welfare state with its focus on institutional quality and equal access to public goods (ibid.353). Serving both individual and communal goals, vaccination fits well with the logics of the universal welfare state model, which, as ethnographic studies have shown, brings together virtues of both individualism and conformity (Gullestad 1989:85). The individual may be ideologically centred in the foreground, yet the social body (the society and the community) constitutes the background, which refuses to be ignored (Gullestad 1992:183 in Bruun, Krøijer & Rytter 2015:21). With this, the individual carries a responsibility for the community and for conforming to its social norms.

Given the traditionally high vaccination coverage in Denmark and the scarcity of national vaccine controversies, the sudden decline in HPV vaccination uptake was a break with earlier social norms. It therefore initiated a search for an explanation that cut across scientific disciplines. Some medical studies explore the nature of the symptoms reported by Danish women and call for more focused attention to be devoted to examining whether the HPV vaccine could have caused these symptoms (Brinth et al. 2015a; Brinth et al. 2015b). As such, various stakeholders such as patient organisations, activist groups and medical professionals have sought explanation in the content of the HPV vaccine, yet a connection between the particular symptoms reported by the Danish women and the HPV vaccine remains scientifically contested (Hammer et al. 2016). On a population level, epidemiological studies attempt to explain the suspected side effects by locating the cause in the women reporting them. Some studies thus find that women referred to HPV clinics with suspected HPV vaccine side effects more often had pre-existing psychiatric conditions, psychological symptoms or frequent general practitioner attendance prior to their HPV vaccinations than women who were HPV vaccinated but were not referred to an HPV clinic (Lützen et al. 2017, Mølbak et al. 2016). With this, they seem to suggest that ‘HPV vaccine side effects’ is merely a new name or idiom (Nichter 1981, 2010) for something already present in the women – an endemic of distress, one might say. Some scholars have suggested that similar reactions seen in Australia and Columbia can be explained as a mass psychogenic illness (Clements 2007; Simas et al. 2019), and several media studies indicate that media coverage influenced the decline in HPV vaccination uptake (Suppli et al. 2018; Hansen & Schmidtblaicher 2019; see also Eberth et al. 2014 and...
Dunn et al. 2015 for the same line of argument, though not based on the Danish context).

In short, HPV vaccination as a global phenomenon entails various configurations, and the explanatory frameworks that have been provided in explaining potential side effects are shaped by distinctive local conditions and inherent disciplinary perspectives. In this article, we make an empirically grounded decision not to ask why: why did the decline in HPV vaccination uptake occur or why did the women experience various pains? Instead, we explore how our interlocutors’ lives were shaped by these particular events and the diffuse explanatory models that were born in their wake. Let us first learn about Sophie.

Sophie: Hope of a healthy future suspended

When Sophie heard about HPV vaccination, she did not have to think for long; of course she wanted to be vaccinated. Who does not want to avoid cancer? Like most people, Sophie knew people with some form of cancer diagnosis and therefore welcomed the opportunity of preventing cervical cancer without hesitation. Perhaps this absence of hesitation is the reason why Sophie never thought to suspect the vaccine when she fell ill. Perhaps it is why she is still not convinced that the vaccine is to blame. Perhaps it is why she is so frustrated to be labelled a hypochondriac or an anti-vaxxer if she merely mentions the possibility of the vaccine causing her pains. When Nielsen met Sophie in 2016, Sophie was in her early thirties and had just returned to work in a laboratory after gaining a Master’s degree. Going back to university was not part of her plan, she explained, but it was the only thing she could do when it became too demanding to sustain a full-time job due to her “deficiencies” [skavanker], as she called them. Sophie had found a way to avoid taking sick leave or unemployment – something many of the women Nielsen met in the HPV clinics were not able to do. Like most of these other women, Sophie was profoundly confined in her everyday life. This confinement grew partly from the pains she experienced and partly from the dismissal and scepticism she encountered in the healthcare system and privately.

At the age of 28, Sophie started experiencing joint and muscle pain and recurrent colds, so she stopped exercising temporarily, assuming that her body needed a break. Sophie described the pain as the type of pain she would normally endure after a workout. After a while, however, the pains became unfamiliar in terms of duration and severity. Sophie did not understand what was happening to her
body and, for a while, she tried to make sense of and understand the signals it was sending her: does this feel like it usually does? Should I seek help? Sophie eventually visited her general practitioner (GP), Lena, who initiated a series of diagnostic tests, such as blood tests, scans, X-rays and physiotherapy. None of these tests provided any answers as to why Sophie’s health was deteriorating, and Lena suggested that Sophie see a psychologist. Lena was convinced that Sophie’s condition was caused by a bad work environment. Sophie admitted that she did not receive much support from her workplace when she missed work due to her pain: »[…] when you don’t have a diagnosis, it’s just me being silly. Then I’m just someone who doesn’t want to work«. Sophie therefore agreed to try therapy, but the therapy did not improve her situation.

At one point, Sophie’s mother, who wanted to help her daughter find an explanation for her suffering, told her about a documentary. The documentary portrayed young women who endured similar pains and diffuse physical sensations and who blamed the HPV vaccine for their situation. »This may be what you’re suffering from«, Sophie recalled her mother stating expectantly. Sophie had never suspected the vaccine as the cause of her suffering, yet, as she traced her medical history, she found a pattern in her care seeking, which began around the time of her second HPV vaccination. Sophie spoke to her GP, Lena, who acknowledged the temporal correspondence and agreed to refer Sophie to the newly established HPV clinic. From here, Sophie’s hopes of finally finding an explanation to her distress took shape, not surprisingly intensified by the referral to an HPV clinic. Yet, in the clinic, the answers she was expecting failed to materialise. Although she felt she had been properly examined, she also felt patronised, as though the clinic was the system’s and her GP’s way of making her feel that »something was being done when actually nothing was being done«. Sophie recalled that, throughout her time in the HPV clinic, she sensed that the healthcare professionals were unwilling to merely entertain the idea that the HPV vaccine had caused her and the other women’s distress. They would refrain from mentioning it and instead focus on how to live an everyday life with pains.

Furthermore, the above-mentioned documentary sparked a broader societal discussion about journalistic integrity and scientific evidence in which Sophie and the other women with suspected side effects became the objects of public attention and apprehension. Several media platforms published articles, features and leaders about the women with suspected HPV vaccine side effects, linking them or the resulting vaccine anxieties to cases of hysteria, gut feelings and myth spreading. These attitudes also reflected Sophie’s general experiences within the
healthcare system, where she encountered physicians who would not take her seriously:

You are met by that feeling of it’s just you [følelsen af at det bare er dig]. They don’t tell you »nonsense, don’t you think you should get out of that hypochondria thing and get going«. They won’t say that, but you often get that feeling when you are sitting in there […] It’s that feeling of not being taken seriously and listened to without there being an ulterior motive.

Most of the women with suspected side effects whom Nielsen met felt like Sophie – rejected, with hopes of a healthy future that were suddenly suspended. We see similar accounts from people suffering from contested illnesses, which often unfold in the painful interplay between a (lack of) diagnosis and a (lack of) legitimacy and lead to feelings of bureaucratic, medical and social dismissal (Good et al. 1992; Aronowitz 1997; Dumit 2006; Kokanovic & Philip 2014). Moreover, the women felt that simply referring to the HPV vaccine in their situation further complicated the already difficult task of gaining legitimacy as being ill – as though, just by mentioning the vaccine as the possible cause of their distress, they compromised the trustworthiness of the vaccine and the system promoting it. In return, the women encountered a growing mistrust in the ways they embodied their pains and suffering. This mistrust pervaded not only their relationships with their GPs and other healthcare professionals but also their relationships with colleagues, friends and family members.

Sophie shared this experience with the other women in this study. None of them was interested in casting unwarranted doubt or suspicion on the HPV vaccine. When they fell ill, they embarked on a journey to improve and to restore their futures – just like Sophie. The HPV vaccine presented just one possible explanation, and many of the women found the temporal correspondence suspicious and worthy of further exploration. They therefore became frustrated that, upon seeking care, they were primarily met with scepticism and dismissal. Consequently, many of them, including Sophie, fell silent about the pairing of their pains and the HPV vaccine. Some of their family members, friends and new physicians do not know the full extent of their sufferings. This silence, which is explored in depth by Nielsen elsewhere (Nielsen, forthcoming), suggests the women had a very narrow space in which to raise their doubts and suspicions regarding the HPV vaccine before being labelled a hypochondriac or an ‘antivaxxer’. The promise of vaccines in a socio-political context of social trust thus normalises some explanatory models while silencing others.
This tendency to withdraw due to sceptical encounters is in line with the findings of Sørensen and Andersen (2016), who explored the experiences of eight Danish women with suspected HPV vaccine side effects. These authors found that the women experienced a lack of recognition from physicians and family, that physicians tended not to take them seriously or listen to them, and that physicians often dismissed their symptoms (ibid.3). As a result, the women have grown distrustful of the Danish healthcare system and live a more restricted and solitary life (ibid.4). Before continuing further into a discussion of the suspension of healthy futures, we introduce Martin, a paediatric specialist, who voluntarily relocated from his usual department to an HPV clinic when the clinics were established in 2015.

Martin: Leave the past and look forward

Based on years of experience as a paediatric specialist, Martin was confident in his ability to care for his patients. That is, until he came to the HPV clinic, where the suggested pairing of his patients’ various pains and the HPV vaccine muddled his overall goal: to help them get better. Martin takes pride in his work as a physician, in improving the everyday lives of the patients who come to see him. One of his main interests is ‘unexplainable pains’ or what he refers to as functional disorders [funktionelle lidelser]. Here, the term ‘unexplainable’ refers to those pains that cannot be accounted for by what medical convention considers a single or a set of possible explanations. For Martin, it makes sense to group unexplainable conditions under the umbrella term of functional disorders, because they share certain characteristics and treatment options. Often, they are not limited to a single organ or part of the body, which is why they are difficult to approach within the highly specialised healthcare system. They are often persistent and disabling for the people suffering from them; and, because they have no medical explanations as yet, the treatment options are based on symptom relief and therapy, where emphasis is on teaching the patients how to cope with pains in their everyday lives. Martin was convinced that most of the women referred to the HPV clinic belonged to this category, and he was convinced that he could help them.

However, Martin discovered that, having received a referral to an HPV clinic, his patients expected confirmation of the pairing of their pains and the HPV vaccine. Since this was impossible, Martin found himself, like many of the healthcare professionals Nielsen met during fieldwork, in a position of having to disappoint
his patients and their relatives, who would often walk out in anger and frustration, convinced that he would not be able to help them.

_It has been absolutely horrible. On the one hand I think, as a hospital, let’s keep a low profile because I don’t want to deal with this. Why do I have to put up with this? On the other hand, I think; somebody ought to stand up and say, »let’s pull ourselves together and do this properly«. That somebody could just as well be me. But what is there to win? You can only lose in this case._

This quotation reflects a deep frustration in Martin, which grew from negative experiences with patients and relatives who would focus on fitting their various sensations of pain within the timeframe of their HPV vaccinations. As Martin explained, most patients suffering from headaches or dizziness could not pinpoint the exact date of debut because such symptoms often evolved gradually. Yet, many of the patients who came to the HPV clinic knew exactly when their pains debuted while still insisting they developed gradually. It was as though the vaccine/side effect pairing forced them to focus on the past, more specifically on the cause of their suffering, instead of focusing on how to alleviate their pains and look to the future, Martin theorised.

While Sophie felt dismissed by her physicians and the healthcare system at large, Martin struggled to care for his patients in a way that meant they would not lose hope of a better future. For him, this was inevitably connected to letting go of the past and ceasing to look for a causal explanation for their suffering. Yet, without a proper diagnosis or at least some explanation, many of his patients told him, they were unable to move forward. Martin understood their frustration. Thus, in order to do his job within the confines of the HPV clinic, he attempted to maintain focus on the unspecific pain experiences presented by his patients while ignoring the (heated) debates about the potential dangers of the HPV vaccine, which had erupted on various media platforms and which sometimes resulted in a polarised exchange of views between different stakeholders. He feared that his patients would fixate on finding the cause of their suffering instead of moving forward. In his opinion, forgetting the vaccine/side effect pairing was a way of bringing the future into the present by having confidence in one’s expectations to get better regardless of the cause of one’s pains. This was an imperative part of his care work, and the inabilities of his patients to do so was the root of his frustrations.
Understanding doubt

By introducing the possibility of preventing cervical cancer altogether, the HPV vaccine was anticipated from the outset as the conqueror of future draconian sufferings, ‘bad deaths’, and the saviour of families. In addition to the wide distribution of HPV vaccines through the childhood vaccination programme and catch-up programmes, the Danish Cancer Society voiced a strong campaign promoting the new ‘cancer vaccine’. Highly anticipated and proclaimed for its potential efficacy, the vaccine carried with it promises of a medical breakthrough that would revolutionise the fields of preventative medicine. This fitted well with the state’s overall prioritisation of cancer disease control, which it had implemented since the early 2000s (Andersen 2017), and ultimately framed cancer as an ‘acute condition’ (Tørring 2014). In this context, the HPV vaccine presented a straightforward way of avoiding cancer; a prick of the skin came to signify a healthy future.

The women with suspected HPV vaccine side effects, including Sophie, engaged trustfully in cancer control. They desired a future without cervical cancer, promised to them by the HPV vaccine and the healthcare system promoting it. When they fell ill after their HPV vaccinations, they shared their suspicions with their GPs and other medical professionals because they trusted them, and the system they represent, to help. Ultimately, however, the system could not cope with their doubts. Approaching this unfortunate dynamic, we turn to Foucault and his three axes of knowledge, power and desire (Foucault 1985:4; Deleuze1985:2). According to Foucault, through desire, individuals are able to focus their attention on themselves and work on their relation to themselves in order to be ethical (1985:5). Sophie desired a cervical cancer-free future more than she feared the risks of vaccination. For her, the HPV vaccination was a step towards a healthy future. It was therefore frustrating for her when the healthcare system, the media and the public reacted with scepticism and disbelief to her and the other women with suspected side effects. It made them feel questioned about their original intentions.

To understand why the women were met with these reactions of scepticism and disbelief, we look to the axes of knowledge and power. The relation between these two axes is illustrated through Foucault’s concept of biopower (1978). Biopower operates – we may say – along the two axes of knowledge and power; the former represented by the disciplining of the individual and the latter by the governance of the population (ibid.140). As we noted above, vaccination may be understood as a communal venture performed individually. Its success relies on the participation of the population. When individuals opt out, it represents a threat to the
population. With reference to C.S. Peirce, doubt in vaccines shatters the social sentiment of inductive reasoning – the «hope, or calm and cheerful wish, that the community may last beyond any assignable date» (Peirce 1878:282). In biopolitics, individual lives are at stake, but the state’s interest – our interests, Peirce would say – do not stop here. They extend to the eternal future of our whole community (Hacking 1990:211).

Returning to the Danish context, at the point when HPV vaccine uptake began to decline, vaccination doubt was simply unwanted. Experts and officials acutely sought to re-establish trust in the vaccine programme by refuting the vaccine/side effect pairing (Mølbak & Hansen 2020). They did so (among other things⁵) by explaining the young women’s pains with other kinds of phenomena, such as general trends of distress and anxiety (Mølbak et al. 2016; Lützen et al. 2017) and by pairing the increasing number of reported HPV vaccine side effects with a suspected media-induced public panic (Suppli et al. 2018; Hansen & Schmidtblicher 2019). These new pairings meant that the label ‘HPV girl’ became less and less synonymous with victims of the system (which was how they were mostly portrayed by legacy media from 2013 to 2015) and more and more synonymous with other forms of health identities. The label HPV girl, in effect, came to refer to a somatising patient or a vaccine sceptic – someone who works against ‘our interests’ and the state’s good intentions. Accordingly, when the women sought help, although fully HPV vaccinated, they were perceived as problematic since they were supposedly incriminating the vaccine. Reflecting back on this development, we might speculate whether parents with daughters due to be vaccinated in 2015 (and in the following years) were reluctant to vaccinate their children solely because they were scared of potential side effects – or also because they feared their daughters falling victim to this institutional and societal labelling. One of the core measures of the state is to ensure a healthy population, and the promise of a healthy future that vaccines carry is rarely questioned. When it is, Sophie taught us, the price can be high – which is why you may need to resort to silence in order to resist societal and institutional attempts to label you psychologically ill or an anti-vaxxer.

Perhaps the duality of vaccines as a technology directed towards the population body yet administered through the individual body explains why there is apparently such limited room to question vaccines within the Danish welfare state. Individuals are expected to adhere to the recommendations of the state and to be able to balance individual and population risks. This is evident when it comes to interpreting bodily sensations as potential symptoms of disease, where indivi-
duals are expected to seek care when necessary without misusing the healthcare system (Offersen et al. 2017). It is also evident when it comes to vaccination, where the individual is expected to side-line individual risks in order to benefit the broader population. Yet, considering the technological qualities of vaccines, previous worldwide vaccine-related controversies and the fact that vaccines literally perforate the skin and dissolve within the body, we should perhaps stop asking questions of why controversies like this occur. We might wonder why they do not occur more often. Or we might, as we attempt here, ask how they rearrange people’s lives in order to understand both their current and future implications. As strategies previously employed to uphold authority become ineffective against these new »ravages of uncertainty« (Douglas 2001:147), we argue that it is imperative to explore the lives that are produced in cases such as this, where individuals and institutions are put under intense pressure when they are encouraged to yield to the production of communal healthy futures.

Conclusions: Revising a healthy future

In this article, we have explored how HPV vaccination promised young women a brighter future without cervical cancer but was also able to create deep rifts in society, leaving both healthcare workers and vaccinated women in a darker and more uncertain position. We did so by presenting the experiences of two main interlocutors: Sophie, a young woman with suspected HPV vaccine side effects, and Martin, a physician working in an HPV clinic. Both of these interlocutors found themselves in difficult situations and having to revise their visions of the future during a challenging period in which the Danish healthcare system was adjusting to a new information and media landscape. We saw the multi-layered trust that Sophie had in the Danish healthcare system; firstly, by getting the vaccine; secondly, by not suspecting the vaccine as the cause of her pain before being presented with the idea (and, even then, she was never convinced); and finally, by continuing to seek care despite her repeated sceptical encounters within the healthcare system. While the price of continuing to seek care has been high for Sophie (being labelled an anti-vaxxer and having to retreat from certain social relations), doing so is the only way for her to sustain hopes of a healthy future. Yet this is not a straightforward process, as we also saw in Martin’s situation. For Martin, caring for his patients meant helping them move forward instead of fixating on the past and the cause of their suffering. He is keen to ensure that his patients can enjoy if
not a healthy future then a least a healthier future than their present conditions dictate. In his opinion, his patients’ unrealistic expectations to discover whether the HPV vaccine caused their sufferings are preventing them from doing precisely this.

From the accounts in this article, it becomes clear that visions of healthy futures, inherent in both the promise of welfare and vaccines, may be interpreted as communal ventures that are vulnerable to temporary suspension or even collapse, which is why revisions are sometimes required. Through these suspensions and revisions, we hint at the multiple expectations shaped by the specific context, such as expectations of the relation between the individual and society within the Danish welfare state, expectations of health care and healthcare seeking, and expectations of the HPV vaccine’s promise to prevent disease and ensure a healthy future. These expectations, we show, generated and sustained not only pervasive uncertainties but also painful feelings of being doubted and silenced by the surrounding society, when various sufferings were publicly paired and then suddenly unpaired with the vaccine. As such, they reflect and highlight inherent tensions of preventative medicine and the Danish welfare society, including the subtle acts of power and resistance that occur within it.

Our aim here has not been to explain why the young women reporting suspected HPV vaccine side effects fell ill or to confirm or disconfirm associations between the vaccine and the sufferings of the young women. On the contrary, we hope to have conveyed the importance of exploring the tacit and the sometimes difficult to define without resorting to a hierarchy of perspectives. Working within a field where catchy headlines, health statistics, social contagion jargon and contradictory viewpoints are deployed and highlighted, creating the impression of an increasing polarisation, this is sometimes easy to forget. The sorts of predicaments that we discuss in this article rather serve to remind us of how deeply bounded or situated sufferings are – an essential point if we wish to understand the lives that are produced in cases such as this.

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Noter

¹ An example of a long-term vaccine side effect is narcolepsy, which followed the widespread use of vaccines against influenza (H1N1) in 2009. Swedish authorities found the relative risk of narcolepsy to be four times higher in vaccinated children and adolescents (born from 1990) compared with unvaccinated individuals. The relative risk estimate translates into an absolute risk of about three cases of narcolepsy in 100,000 vaccinated (World Health Organization 2011).

² Herd immunity is the shared protective effect of a population that occurs when a sufficiently large proportion of the population is immunised and which is a great incentive for public funding (Danish Health Authority 2018; Sobo 2016).

³ To ensure anonymity, our interlocutors have been given pseudonyms and further identifiable attributes are omitted.

⁴ With the concept of “vaccine/side effect pairing”, we are not referring to the adverse effects listed on any patient information leaflet, including the HPV vaccine. On the contrary, we are referring to the specific conceptions and suspicions about a possible pairing (scientifically proven or not) between the HPV vaccine and various sufferings that spread throughout Denmark following the vaccine’s implementation.

⁵ In 2015, upon an appeal from the Danish state, the European Medicines Agency (EMA) assessed the evidence of a causal association between the HPV vaccine and two syndromes, CRPS and POTS, of which case reports came from Australia, Germany, Japan, USA, and Denmark (EMA 2015:3). The EMA concluded that the available evidence did not support a causal association but the report motivated the director of the Nordic Cochrane Centre, Peter Gøtzsche, to accuse the agency of scientific misconduct. While the EU Ombudsman declared that there was no maladministration in the EMA’s handling of its safety review, Gøtzsche reappeared when the Cochrane collaboration published a safety review of the HPV vaccine in 2018 (Arbyn et al. 2018). Along with two other members of the Nordic Centre, Gøtzsche published what they found to be important limitations in the review (Jørgensen et al.2020 [2018]). This caused internal disagreement within the Cochrane network and resulted in the dismissal of Gøtzsche as the Director of the Nordic Cochrane Centre. Following his dismissal, Gøtzsche opened the ‘Institute for Scientific Freedom’.

References


Dumit, Joseph 2006. Illnesses you have to fight to get: Facts as forces in uncertain, emergent illness-es. Social Science & Medicine, 62, pp. 577–590. doi:10.1016/j.socscimed.2005.06.018


Lützen, Tina Hovgaard; Bech, Bodil Hammer; Mehlisen, Jesper; Vestergaard, Claus Hostrup; Krogsgaard, Lene Wulff; Olsen, Jorn; Vestergaard, Mogens; Plana-Ripoll, Oleguer; Rytter, Dorte (2017). Psychiatric conditions and general practitioner attendance prior to HPV vaccination and the risk of referral to a specialized hospital setting because of suspected adverse events following HPV vaccination: a register-based, matched case-control study, Clinical Epidemiology, 9, 465-473. DOI: 10.2147/CLEP.S135318


Nielsen, Stine Hauberg (forthcoming). Silencing HPV Encounters. Exploring the experiences of young women suffering from suspected HPV vaccine side effects.
Simas, Clarissa; Munoz, Nubia; Arregoces, Leonardo & Heidi J. Larson (2019) HPV vaccine confidence and cases of mass psychogenic illness following immunization in Carmen de Bolivar, Colombia, Human Vaccines & Immunotherapeutics, 15:1, 163-166, DOI: 10.1080/21645515.2018.1511667
Suppli, Camilla Hiul; Hansen, Niels Dalum; Rasmussen, Mette; Valentiner-Branth, Palle; Krause, Tyra Grove and Kåre Mølbak (2018). Decline in HPV-vaccination uptake in Denmark – the association between HPV-related media coverage and HPV vaccination. BMC Public Health,18:1360. doi.org/10.1186/s12889-018-6268-x
Towghi, Fouzieyha (2013). The biopolitics of reproductive technologies beyond the clinic: Localizing HPV vaccines in India. Medical Anthropology, 32(4), 325. DOI:10.1080/01459740.2013.769976

