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Mezza, M.; Blume, S.

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Turning suffering into side effects: Responses to HPV vaccination in Colombia

Maurizia Mezza^{*}, Stuart Blume

Amsterdam Institute for Social Sciences Research, University of Amsterdam, the Netherlands

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ABSTRACT

How do unpleasant post-vaccination symptoms become recognized as vaccine ‘side effects’? In this paper, we argue that it is not necessarily the logical outcome of scientific verification that it is said to be. The paper draws on an ethnographic study carried out in a small town, El Carmen de Bolivar, on Colombia’s Caribbean coast from February through May 2019. In 2014, hundreds of girls in the town reported a range of mysterious symptoms following mass vaccination against the Human Papilloma Virus (HPV). Denying the girls’ insistence that their symptoms were due to the vaccine, the official diagnosis was Mass Psychogenic Illness. Comparing these events with studies of controversial responses to other vaccines, we suggest that the pathway from post-vaccination symptoms to ‘side effects’ is cognitively and socially complex. In particular, it is context-dependent. Drawing on research in medical anthropology, sociology and STS, we argue that the official diagnosis was influenced by the subjects’ marginal status; by a projection of the region’s violent past onto individual inhabitants; by health professionals’ commitment to a restricted notion of evidence (devaluing patients’ own accounts); and by an institutional inability or unwillingness to stand against ‘global consensus’, which deems HPV safe.

1. Introduction

Through the second half of the twentieth-century vaccines came to be seen as the most effective, and the most cost-effective, tool of public health. They became increasingly central to preventive health: the basis for smallpox eradication and the Expanded Program of Immunization established by the World Health Organization in 1974. On occasion, public controversy regarding the safety of a vaccine led to a loss of confidence in the vaccine or to claims for damages. Worried at the prospect of being held liable for vaccine-related injury, in the United States some pharmaceutical companies abandoned vaccine production. In response, and in order to reassure the industry and protect the vaccine supply, in 1986 the United States Congress passed the National Childhood Vaccine Injury Act (Blume, 2017, p. 150). One of its requirements was that any ‘adverse event’ following, and perhaps due to, vaccination be reported to a central registry. Established in 1990 and managed jointly by the Food and Drug Administration (FDA) and the Center for Disease Control (CDC), this registry became known as the Vaccine Adverse Events Reporting System, or VAERS. A few other countries developed similar systems, among them the SiVigila in Colombia.

Despite the considerable literature addressing social and cultural

dimensions of vaccine resistance around the world, few studies have examined how experiences following immunization sometimes become legitimized as ‘vaccine side effects’. What are vaccine side effects, and how are they identified as such? This paper constitutes an exploration of the processes by which impairments, syndromes, signs, or symptoms become credibly attributed to a vaccine, and the processes by which such attribution or attachment is fended off. Drawing on scholarship in medical anthropology, sociology and STS, we argue that the attribution of unwanted symptoms to a vaccine, the processes by which they become ‘side effects’, are both complex and context-dependent. Relations between symptoms, subjects, researchers and vaccines shape what does or does not become a vaccine side effect.

The focus of this article is the controversy that erupted in El Carmen de Bolivar, a small town on the Atlantic coast of Colombia. In 2014–2015 after immunization with the HPV vaccine Gardasil 4, a group of girls started complaining of strange and unexpected symptoms. They attributed these symptoms to the vaccine which they had recently received. After a few months of investigations conducted by the National Health Institute (Instituto Nacional de Salud or INS), the Government reported that it was a case of collective hysteria. The hysteria diagnosis shifted the focus from the vaccine and the symptoms to the subjects. An

^{*} Corresponding author.

E-mail address: m.mezza@uva.nl (M. Mezza).

official narrative was constructed in which symptoms reported were attributed to qualities of those reporting them. Not the message, but the messenger, was problematized: a discursive strategy, which Robert K. Merton noted in his classic reflection on the sociology of knowledge (Merton, 1968). The vaccine is thereby shielded from critique. What makes this possible? How did a large group of adolescents, convinced that their bodily suffering was due to a recent vaccination, find themselves, not the vaccine, the focus of explanation?

1.1. What is a side effect?

In medical literature, 'Adverse Reactions' (AR) are distinguished from 'Adverse Events Following Immunization' (AEFI). The former refers to those adverse events for which a causal relation with vaccination has been established. The latter is "a health problem that happens after vaccination that may or may not be caused by a vaccine. These events may require further investigation" (Shimabukuro et al., 2015). In principle, anyone can report an unwelcome symptom following vaccination to an adverse event reporting system such as VAERS. However, the information flow pooled in these databases is categorized, statistically elaborated, and assessed with specific tools and protocols (Chandler et al., 2019). When these operations show an alarming number of reports, epidemiological studies may be carried out, to establish the symptom's cause, and to confirm or reject a causal link with the vaccine. Below we present two cases where negative responses to a vaccine were accepted as such, though through quite different processes.

The treatment of a vaccine called RotaShield exemplify the VAERS system at work. RotaShield had been shown to confer substantial protection against a particularly dangerous form of diarrhea. Approved in 1998, the vaccine was rapidly taken up in the USA. In July 1999, after receiving alarming reports, the CDC published preliminary epidemiological data suggesting that 15 cases of intussusception (a rare but potentially fatal blockage of the intestine) were probably linked to the vaccine. A few months later, the U.S. Advisory Committee on Immunization Practices and the CDC withdrew their recommendation for RotaShield. Although it was not understood how RotaShield could have caused intussusception, the manufacturer voluntarily withdrew it from the market (Bines, 2006).

A second example shows a process by which certain symptoms became successfully attached to a vaccine despite conflicting scientific evidence. In 2009, 60% of the Swedish population was vaccinated with Pandemrix to prevent H1N1 flu. When toward the end of the pandemic, reports of narcolepsy emerged, controversy about its relation to the vaccine emerged (Lundgren and Holmberg, 2017). There is still no consensus within the scientific community as to whether the relationship between Pandemrix and narcolepsy was causal, but the link between vaccine and suffering was rendered sufficiently credible in *regulatory and legal* contexts. The vaccine authorization was not renewed, and Pandemrix was withdrawn from the market. Some families were awarded compensation, though without the manufacturer admitting liability (Traynor, 2019).

While the attribution of intussusception to RotaShield took place through epidemiological studies and appears straightforward, the second example shows a case in which research findings are disputed in scientific contexts but finally accepted in other contexts.

These two cases provide two different examples of the pathway from post-vaccination symptoms to 'side effects'. In both cases the attachment of post vaccination experiences to a vaccine was successful even with a lack of conclusive scientific evidence, differently from the controversy that exploded in Colombia following vaccination with HPV.

2. Making vaccine adverse reactions

Over a period of more than forty years, researchers in STS and the sociology and history of science have been exploring the ways in which scientific knowledge is socially produced. Though their approaches

differ in innumerable ways, they share a common focus on science less as a body of knowledge, as on science as a set of practices (Pickering, 1992). It is through its practices, its tools, and its social strategies that the 'facts' of science are made (Latour and Woolgar, 1979; Clarke and Fujimura, 1992). In line with this body of work, we aim to foreground the processes and the practices involved in 'making' vaccine adverse reactions: that is, in attaching unintended and unwanted experiences following immunization to a vaccine. We hope to illuminate the complexity of these processes, involving as they do protocols and methods, and context-dependent social imaginaries. They also depend on hierarchies of evidence. Within the biomedical paradigm, organic markers, with their overwhelming explanatory weight, are key to achieving a diagnosis, and hence recognition and support. Where such biomarkers are lacking, as in many 'emergent illnesses', patients themselves can become the focus of biomedical suspicion (Dumit, 2006).

We hope to expose the power dynamics that enable certain connections to achieve legitimacy at the expense of others. Problematizing the exclusion of subjectivities deemed marginal by virtue of gender, age, class, race, or social identity, we draw on an intersectional approach. Intersectionality makes visible forms of power and oppression that are invisible within single-axis analysis (Mollett, 2017). We attend to the call for "complexing the fabric of power in post-colonial societies" (Curiel, 2007, p. 100). The intersections between gender, age, class, and race crucially shape the production of validated knowledge of vaccination. So too does geography, since scientific knowledge is produced in global networks marked by hierarchic relations between 'center' and 'periphery', and their associated epistemic hierarchies (Appadurai, 2000).

This study seeks to connect the complexities and multiplicities embedded in the making of evidence with the lived experiences of excluded subjectivities, opening a space in which voices silenced by homogenizing practices and power mechanisms can be heard.

3. Methodology

In order to address the processes through which certain experiences do or do not become attached to a prior vaccination, we collected and analyzed interviews, field notes, documents and newspapers through an ethnographic approach. Ethnography allowed us to focus on how people narrate their lives while providing the context in which data are (co) constructed. It enabled us to locate subjects' narratives within appropriate networks of meanings and practices. The first author conducted fieldwork in Colombia from February to May 2019. Existing personal contacts facilitated access both to the community in El Carmen de Bolívar and to national institutions in the capital city, Bogotá. Participants were recruited using selective and snowball sampling.

In El Carmen de Bolívar, twelve girls were interviewed, all of whom had been vaccinated at school in 2013 and 2014. Of the twelve girls, two did not develop any worrying post-vaccination symptoms. This paper reports the experience of five of the twelve girls. They have been selected because (1) they belong to the first group of girls who developed the symptomatology, and (2) they were included in the epidemiological study conducted by the National Health Institute. Their names and personal details have been changed in order to protect their anonymity. Angelica and Sandra were interviewed together at the home of Angelica's parents. Alejandra, Beatriz and Liliana were interviewed singly. While Beatriz was interviewed at her home in El Carmen de Bolívar, Alejandra and Liliana were interviewed in the two cities where they currently live, in cafés. Sixteen health professionals from regional and national medical and policy-making institutions were also interviewed. These were recruited from nine institutions (Table 1). Because of the small size of the groups in which they work, even noting an interviewee's gender would risk revealing her or his identity. In order to adequately protect interviewees' anonymity, they are referred to simply as *health professionals*. They were all interviewed separately, in their offices. All interviewees participated voluntarily in the study, agreed to

Table 1
Interviews with the health authorities.

Institution	Participants	Profession	City
National Health Institute	4	Epidemiologists	Bogotá
National Institute of Cancerology	2	Medical doctors	Bogotá
Ministry of Health	2	/	Bogotá
National Food and Drug Surveillance Institute	2	/	Bogotá
National Medicine Academy	1	Medical Doctor	Bogotá
Institute of Health Technologies Evaluation	2		Bogotá
Hospital Nuestra Señora del Carmen	1	Nurse	El Carmen de Bolívar
Provincial Administration	1	/	Cartagena
Colombian League against Cancer	1	Medical Doctor	Bogotá

interviews being recorded, and gave written consent to be quoted anonymously in publications. All interviews were semi-structured, based on a phenomenological approach, and lasted between 60 and 120 min. Interviews were recorded, transcribed and manually coded. Quotations have been translated from Spanish as literally as possible.

Prior ethical approval of the study was given by our home institution. The girls in our study could be considered vulnerable by virtue of age and social status. Particular ethical and methodological challenges were involved. Because the girls were young (age range 16–22), they were contacted through their families, whose prior consent was obtained. In order to avoid arousing false expectations, it was made clear that the research would not establish the symptoms' cause nor whether the vaccine was responsible. The girls were not being asked to recall painful experiences for the first time since many of them had previously been contacted by journalists and researchers. Though an ethical difficulty is thereby avoided, a methodological complication must be acknowledged. The girls' accounts may have evolved through repeated retelling (and through interviewers' responses) and as the girls themselves matured over the intervening four years (Haglund, 2004).

4. A gendered virus and a gendered vaccine

The human papillomavirus, transmitted sexually and implicated in almost all cervical (and some other) cancers, is recognized as a major public health threat. In 2006–7, the first HPV vaccines became available. The Food and Drug Administration (FDA) approved Merck's Gardasil 4 in 2006, while the European Medicines Agency (EMA) approved GSK's Cervarix in 2007, in both cases for girls and young women only. No modern vaccine introduction had been accompanied by a similar level of public debate, though what exactly was debated and by whom differed from country to country (Haas et al., 2009). In the USA, for example, a recommendation for HPV vaccination to be made compulsory provoked powerful opposition from an unusual alliance. The vaccine is most effective when given before the start of sexual activity, and conservative Christians viewed it as a threat to young girls' chaste innocence. Feminists objected to what they saw as a further medicalization of women's bodies (Löwy, 2011). Subsequently, controversies around HPV vaccines re-emerged in several places (US, Japan, India, the UK and Spain, among others). Acknowledged adverse reactions are mild and include pain, redness, and swelling at the injection site or, more rarely, fatigue, vomiting, and syncope. Any such reactions are supposed to resolve spontaneously and rapidly. In Japan, which has very stringent standards for risk acceptance, several adverse events, including syncope, Complex Regional Pain Syndrome, and impaired mobility, had been reported. The Health Ministry withdrew its recommendation for the HPV vaccination in 2013, though it remains available on request (Morimoto et al., 2015). In Denmark, the Danish Medicine Agency received an increasing number of reports linking the vaccine to symptoms including dizziness, headache, and sleep disorder, occasionally also musculoskeletal

symptoms. Brinth et al. (2015), who studied the girls affected, concluded that a causal link to the HPV vaccine could be neither confirmed nor dismissed. They concluded that "further research is urgently warranted" (Ibid., p. 4).

Social scientists have devoted a good deal of attention to HPV vaccines. They have foregrounded how assumptions about sex, gender, class, race and 'development' shaped the production of epidemiological data (Löwy, 2011), health policy (Wailoo et al., 2010; Maldonado, 2017) and promotional campaigns (Mamo et al., 2010). Maldonado (2015, 2017) has provided a careful analysis of how evidence for the cost-effectiveness of the intervention was crafted in Colombia. Discussing how numbers were used in decision-making processes, he shows how these were sexed and de-sexed as the policy discourse moved from justifications of public-funding to public health campaigns. Gardasil was introduced in the Colombian National Immunization Program, after a long and complex process, in August 2012 (see Maldonado, 2015). The Ministry of Health set out to vaccinate at least 80% of females aged 9 years or more. By 2013 Colombia had one of the highest rates of HPV vaccination coverage in the world: over 90%. This decreased drastically when the first rumors about supposed adverse reactions began to circulate. The fact that by 2016 the coverage rate had fallen to 14% is generally attributed to events that occurred in late May 2014 in a small town on the country's Caribbean coast (Simas et al., 2019).

In El Carmen de Bolívar HPV vaccination took place through a school-based immunization program. Official guidelines stated that girls' families were to be informed about the virus, the vaccine, and the vaccination process. They were to be offered the possibility of declining the vaccination (Ministerio de Salud y Protección Social (MSPS), 2012). In practice, families received no information and consent was rarely requested. As the girls remember it, the teachers forced them into getting vaccinated. In fact, the teachers themselves were unprepared. The teachers had been ordered to ensure the campaign was successful. So, they did indeed force the girls to be vaccinated. With no information provided to the girls or their families, and with no possibility of refusal, vaccination was experienced as coercive and abusive (Tellez, 2018).

Towards the end of May 2014, fifteen girls in El Carmen complained of tachycardia, difficulty in breathing, fainting, seizures, and numbness in their limbs (Martínez et al., 2015, 43). Each day several new girls presented the same range of symptoms. By September, it was common to see a motorcycle speeding toward the hospital Nuestra Señora del Carmen, with an unconscious girl on the back. In a few months, the number of girls affected had increased dramatically: from the first fifteen to five hundred by September (ibid.,41), six hundred by October to about a thousand in 2019 (according to the community). The girls and their families blamed the HPV vaccine, and the provincial administration sent an interdisciplinary team to the town to investigate. Their report rejected the girls' attribution of their symptoms to the vaccine. How did the girls come to associate their experiences with the vaccine? And how did the health authorities come to reject their claim, diagnosing them instead with Mass Psychogenic Illness?

5. Findings

Below we present the narratives of five girls from El Carmen de Bolívar, which describe how they began to associate their malaise with the vaccine. From their perspective, there is more than a temporal association between the impairments and the vaccine. Despite the varied symptoms they describe, there was a common pattern to their experiences. Mild symptoms appeared after the first shot and intensified with the second shot. As far as they could see, only vaccinated girls were affected. Thereafter we describe how public health authorities responded to the girls' claims. We draw on the epidemiological study that diagnosed the girls with MPI (Martínez et al., 2015), interviews with the health authorities, and a brief presentation of debates in the Colombian scientific community, which was by no means united.

5.1. Memories from El Carmen de Bolívar

The girls' recollections of being vaccinated include a variety of what are considered mild vaccine side effects: dizziness, headache, fever, bleeding and bruising around the injection point. None of them worried too much at first. According to the vaccination guidelines, effects like these are common and should disappear within a few days (MSPS, 2012, p. 23). All the girls interviewed assumed these were normal reactions to the vaccination. Only Sandra visited the hospital once because she became short of breath, though tests showed nothing. It was only in March 2014, after the second HPV shot, that she began to worry. Her previous symptoms became worse, and some new ones appeared. Alejandra, who barely remembers the first shot, remembers the second one vividly. Not only did she develop a headache and experience her body as "very heavy", but she noticed that five other girls fainted right after the shot. A month later, Alejandra's symptoms had still not gone. She began experiencing sudden dizziness, as well as numbness in her limbs. When she complained, her mother answered that she probably had low bodily defenses or "teenager issues". Only after Alejandra fainted in the bakery did her family take her complaints seriously. Sandra's symptoms were also attributed to low blood sugar until, after the second shot, the symptoms became worse. Moreover, she suddenly developed intense fevers, lost weight, often experienced tachycardia, and developed purple eye sockets. Liliana's symptoms also became worse after the second shot. Angelica recalls that she started feeling very tired and that she developed rashes. According to official guidelines, tiredness and general rash are acknowledged adverse reactions, which may appear 15–30 min after the shot (MSPS, 2012). Beatriz can pinpoint exactly when her health problems began. A week after she had been vaccinated, she was at school and walking back to her classroom. She suddenly collapsed, only to wake up in the hospital. A few hours later she was back home, since the doctors said she had *nothing*. However, that same night she fainted again, "I felt my whole body cramped". Nevertheless, the worst moment came two days later when she started feeling that she could not breathe: "I thought I was drowning. I felt like there was not enough air". All of the girls were convinced that immediately after the second shot something changed in their bodies. However, it took a while before they or their families related the general tiredness, the fainting and the fevers to the vaccine.

Beatriz, Alejandra and Sandra were briefly hospitalized and soon discharged. Since there were no organic signs, the doctors, as well as the girls' families, thought that it was just low blood sugar. It was only later, when more than fifteen girls fainted in the school Espiritu Santo, that they, their families, and the local health authorities, recognized that something more than normal "teenager issues" or "low body's defenses" was involved.

May the 30th was the first day I was brought to the hospital. We were all in the classroom when something weird happened. We heard that a girl fainted, that this other girl could not breathe ... and then I started feeling weird as well. I had *tachycardia*, and I felt that I was not able to breathe properly. I could not walk home, so my mother brought me to the hospital. I fainted, and when I woke up in the hospital, we saw that there were many girls from my school (Interview with Sandra, 14/04/2019).

This was when the El Carmen de Bolívar events started, according to the official account. For the press and the health authorities, the May 30, 2014 marked the beginning of the symptomatology. However, according to the girls, it marked the day of its recognition. As the girls began to talk with one another in the hospital, as they and their families discussed the symptoms they had been experiencing, their perception changed. Liliana recalls, "we started linking the symptoms with the vaccine only after the first mass crisis. I saw that my schoolmates were experiencing the same as me". Experiences that individually could have been linked to low blood sugar now assumed a different significance.

The first few times I fainted, I thought about what I ate, or if maybe I forgot to eat, or if I ate something that poisoned me because I had never fainted before. But after seeing all these girls fainting, and that they were only girls, because no boy ever fainted like us, contrary to what they said, and that it was right after the vaccine ... it made me think (Interview with Beatriz, 18/03/2019).

Alejandra remembers that it was when she saw many girls with similar symptoms that she began to connect them with the vaccine. After the first general crisis, more girls started fainting, also in different schools. However, "the bizarre thing is that we were all the same age".

The symptoms, which had progressively intensified, acquired a new and different significance through what had become a collective *crisis*. In the girls' narratives, *the crisis* is a constant, though they describe very different combinations of symptoms. Liliana, for instance, tells of

difficulty in breathing, tachycardia, headaches, and numbness in the extremities, mainly the lower ones ... you feel like if your brain disconnects from you. I feel as if my soul is leaving me because I cannot breathe ... when a crisis is coming, I feel my heart beating very fast, I was saying 'mami please take me, I cannot breathe'. I felt the trachea closing and pressure on my chest ... like if I was compressed between two walls. When I arrived at the first aid, and they gave me oxygen, I started feeling relieved (Interview with Liliana, 19/03/2019).

Beatriz could stay unconscious for as much as 30 minutes, twisting her hands and feet. When she woke up, her whole body felt exhausted: her bones, muscles, and chest hurt, and her throat was burning. "When I woke up in the hospital, my chest was red from how long they tried to reanimate me". (Reanimation was attempted by pressing down hard on the chest). "Those crises were like a switch that you turn on and off", Alejandra remembers,

I could feel normal talking to you, but suddenly I could start feeling intense headache, pain in my spine, numbness in my legs, tiredness, and that I could not breathe; I was suffocating. And then I fainted. My mother told me that while I was unconscious, I had seizures, foam came out of my mouth. Sometimes I vomited blood (Interview with Alejandra, 8/04/2019).

Alejandra mentions the impressive strength she had during those *crises*. Once she had a crisis while she was walking alone, and falling, she broke a leg. The longest *crisis* Alejandra experienced was around 8 hours. Sandra's crises used to start with tachycardia and chest pain, "the pain was like a pressure on the chest", and then her limbs became numb, and a tingling filled her body. Within a few seconds, she stopped feeling anything and fainted. While she was unconscious, she was trembling, sometimes her hands and feet became rigid, and her eyeballs rolled up into her head. Once, she remained unconscious for 40 minutes "When I woke up, I was very tired. I felt like I had been walking all day, I was completely gone". Angelica, who experienced much milder symptoms than her classmate, tried to explain what she had seen. "It was like seeing a fish out of the water, you know how it does ...", she says, miming small jumps with her hands. Then, pointing at Sandra, she continues, "she was like a fish jumping because it had no oxygen".

Alejandra recognizes that "at the beginning, the doctors and the nurses were very worried. But they were giving us random medications [mostly ibuprofen] because they didn't know what was going on". However, after clinical tests showed no organic anomaly in the girls' vital signs, they began to be mistreated. She continues, saying that after the first results in the hospital "they [health workers] were always whispering, saying that we were crazy, that we were horny or possessed, that this was not the vaccine, it was lack of a man, and that we were faking it for the money". The fact that the first collective crisis occurred in a nuns' school fed the rumors. "We could not have pain here," Beatriz says, pointing at her stomach, "because we were aborting according to them, or we were pregnant". Sandra's clinical record wrongly reported

that she was pregnant at her first hospitalization.

5.2. An official response

In June 2014, immediately after the first collective crisis, the official investigations began. The Colombian National Health Institute (INS), following unexpected and increasing number of reports from its SiVigila database, conducted a field visit in El Carmen de Bolívar. A team of visiting experts produced two reports. One, “Outbreak of unknown etiological event in the municipality Carmen de Bolívar”, is publicly available (Martínez et al., 2015). It is based almost exclusively on the analysis of the girls’ hospital records. A request to consult the other, a case-control study, was refused. The published INS report focuses on the period from late May to October 2014. A number of hypotheses regarding the possible etiology of the symptoms were considered. One concerning intoxication by either water, food, pesticide or psychoactive substances was dismissed through laboratory tests. Other possibilities were an adverse reaction to the HPV vaccine and a socio-psychological phenomenon, for which their use of the Ouija board was taken as evidence (ibid., p. 48). Even if the Ouija board hypothesis was immediately dismissed, the possibility of a socio-psychological explanation remained (Tellez, 2018).

As prescribed by the AEFI assessment protocol, the epidemiologists compared the girls’ symptoms with possible adverse reactions to Gardasil as listed in the official vaccination guidelines. The guidelines distinguish between possible ‘mild’ and ‘serious’ side effects, specifying frequency, incidence, expected time of manifestation, and duration (MSPS, 2012, 23). Though some of the symptoms reported by the girls appeared as expected, both the frequency and the timing of their appearance diverged significantly. “This is the protocol”, one of the health professionals explained when interviewed. “I say that this is not a vaccine side effect because it does not match the side effect description in terms of timing and frequency”. The epidemiologists and health authorities from Bogotá however had never met the girls. They compared the symptoms as they were recorded in clinical histories. Presenting the epidemiological approach adopted, the report provides a brief description of the municipality. Together with some geographic and demographic data, socio-economic factors are highlighted. In the results session of the report, the authors stress the families’ low socio-economic status together with the lack of biomedical facts. “Based on the laboratory evidence, the case-by-case follow up, and the scientific literature review, there is no relation between the public health event and the vaccine administration” (Martínez et al., 2015, 73).

Because ‘no relation’ was found, the events which had occurred in El Carmen were designated ‘Mass Psychogenic Illness’, or MPI (Martínez et al., 2015; Simas et al., 2019). MPI is a psychiatric category that belongs to the main cluster of conversion disorders and delusional disorders, characterized by nervous system disturbance exhibited unconsciously with no corresponding organic etiology. The community was informed of the investigation results, which were publicly endorsed by the Health Minister and by the President of the Republic. With the vaccine having seemingly been exonerated of any guilt, the vaccination campaign continued. A few professionals were unconvinced, however, questioning the government’s approach and the decision to continue vaccinating with Gardasil (Sanchez-Gomez et al., 2014). Suspecting that the symptoms were indeed connected with the vaccine in some way, they asked for a new in-depth study. The possibility of autoimmune reactions could not be ruled out. Moreover, even if the girls’ symptoms were a psychogenic reaction, this had been triggered by the vaccine. It followed that an approach focusing on the vaccine as well as on the community was needed. Sanchez-Gomez et al. were not alone, either in Colombia or beyond. Other medical scientists also pointed to the possibility of links between Gardasil and autoimmune reactions (Anaya et al., 2015). Furthermore, in a letter from the Colombian National Academy of Medicine to the Minister of Health, a group of doctors, noting the difficulty of establishing possible autoimmune reactions,

asked for the HPV vaccination campaign to be reviewed. The government resisted any suspension of the vaccination program, but as part of a commitment made to the community of El Carmen de Bolívar it commissioned the Institute of Health Technologies Evaluation (IETS) to conduct a systematic literature review aimed at assessing the vaccine’s safety. The IETS is a public-private organization that collects evidence to inform healthcare policy-making. Having reviewed 112 publications, the authors concluded that the vaccine “has an appropriate safety profile” (Fuentes et al., 2016). However, it was impossible to exclude the possibility of rare adverse events, in particular, those related to autoimmune diseases. Some members of the scientific community were in turn critical of these nuanced conclusions.

6. Discussion

In the dispute between the community of EL Carmen de Bolívar and the government, the girls’ claims were not seriously considered by the health authorities charged with assessing them. Rather, the girls’ experiences were delegitimized. Analyzing the controversy, Maldonado (2017) argues that the hysteria diagnosis was used to downplay suffering which clashed with institutional positions. Scientific evidence became a tool for legitimizing the accounts of some health authorities, and for delegitimizing the accounts of the girls and their families. However, despite the government’s attempts to provide a unique and authoritative scientific narrative, the medical community was anything but united in its interpretations of the girls’ experiences. That some medical experts questioned the vaccine suggests that the ‘scientific evidence’ was not wholly consistent. The outcomes of other vaccines’ controversies, such as those around Rotashield and Pandemrix discussed earlier, indicate that unwanted symptoms can become attached to vaccines in different ways, even in the absence of conclusive scientific evidence.

The Rotashield and Pandemrix controversies share some common features, which distinguish them from the case discussed here. The differences enable us to highlight some of the dynamics at play. First, in the case of Rotashield and Pandemrix, the symptoms reported corresponded to biomedically accepted diagnoses with recognized etiology and patterns. Second, controversy arose in high-income countries, where the complainants possessed the resources needed to mobilize public opinion, influence political decision-makers, or go to the courts claiming damages. Third, alternative vaccines existed or were under development so that any difficulties for public health would be temporary.

Below we discuss the implications of presenting with symptoms that do not correspond to biomedical codes from an intersectionally marginal position and within a subordinate system of knowledge production (Diniz, 2017). We argue that the etiology of the girls’ symptoms and the lack of biomarkers reinforced and was reinforced by their marginal status. Colombian health authorities’ attachment of the symptoms to the girls was facilitated by the nature of the symptoms and by the marginality of both of the girls and of their community. It was rendered imperative by what was at stake for the Colombian health authorities.

6.1. Handling complexity and making diagnostic sense

Beatriz, Alejandra and Angelica reported that before proceeding with the clinical tests, and before receiving negative test results, the health professionals from the local hospital were attentive to the girls’ claims. However, when no organic anomaly was found, analysis refocused on the girls’ mental health. One health professional from the INS explained, “checking the organic part, we see that there is no explanation for this [the symptomatology], so this is something that needs to be approached by psychologists and social workers rather than by us”. The lack of an organic marker opened a space for uncertainty. The shift from trying to make a diagnosis to viewing the patient with suspicion has been noted in several anthropological and sociological studies of little-understood

syndromes, or ‘emergent illnesses’ (Markovic et al., 2004; Dumit, 2006). In these analyses, two processes are mostly addressed. One is the hierarchical relationship between forms of knowledge, in which the professional community is unwilling to attach much weight to patients’ experiential knowledge that clashes with biomedical codes and explanations (May 2006; O’Donovan and Madden, 2018; Boardman, 2014). The second reflects the legitimatory function of diagnosis. Lacking a medical diagnosis, sufferers risk being denied social recognition and possible benefits. They may be accused of simply faking their symptoms. These mechanisms are clearly foregrounded in the accounts of Swedish parents reported by Lundgren (2015). The diagnosis of narcolepsy was key to accessing medical assistance, legal procedures and social recognition, as well as justifying additional scientific studies. However, obtaining a diagnosis was “a painful waiting experience” (Lundgren, 2015, p. 154). The parents themselves suggested narcolepsy as a possible diagnosis, but they ran into doctors’ initial skepticism. Narcolepsy is a rare condition. Nevertheless, even if its etiology is still a matter of debate, there are several biological markers accepted as providing validation (Hauser, 2011). This is not the case for the syndromes attributed to the HPV vaccine in Colombia, as well as in Denmark and Japan. All these syndromes are linked to emergent illnesses, which are not only difficult to diagnose but also biomedically controversial (Cervantes and Doan, 2018). Gaining a clear, biomedically accepted diagnosis is crucial. In the case of the HPV vaccine, the lack of consensus on the symptoms claimed, and, potentially, lack of knowledge about autoimmune diseases, delegitimized them in the eyes of physicians and epidemiologists.

6.2. Intersecting marginalities

Even before the INS report diagnosed the girls with collective hysteria, doctors and nurses in the local hospital attributed their symptoms to supposed sexual behavior, mental disorders or economic interests. For the medical staff of the local hospital, the lack of biological markers magnified certain traits of the subjects: their gender, age and class, which mutually constituted each other, shaping the girls’ experiences and legitimizing their exclusion (Elmhirst, 2011; Mollett, 2017). Moreover, in the eyes of the health researchers sent from the INS in Bogota, they were also inhabitants of an “out-of-the-way geographic location” (Shields, 1991, p. 3). El Carmen de Bolívar is the central municipality of the region Montes de María, a rural area on the Atlantic coast of Colombia, a thousand kilometers north of Bogota. A “social periphery” (ibid.), nationally known for its *folkloristic* dances and music (see Mignolo (2009) for a decolonial perspective on folklore), for the fertility of its land, and for the violence of the conflict it experienced, between 1997 and 2003. In the memories of the Bogota health professionals, this sense of the distant region persists. During the interviews, they often remembered the massacres that took place in El Carmen de Bolívar: the historical context in which the girls had grown up, which, according to them, back up the diagnosis of MPI. This imaginary contributed to shaping outsiders’ interpretations of the girls and their families’ accounts. Some researchers saw the fact that the girls and their families sometimes used medical terms as an indicator of their duplicity. As one professional put it, “some of the parents used a language too technical when their educational level was not so high”; “Some of these families live in an *invasión* [Illegal settlement], but they used a professional language”. It was taken for granted that people who are poor are necessarily ignorant, undermining the credibility of subjects’ statements.

‘Hysteria’ as a biomedical category has traditionally been associated with gender and age and has been contested as a category invented by western psychiatry (Kleinman, 1977). Goldstein and Hall (2015) analyzed the case of teenagers in the rural US, who, also affected by mysterious symptomatology with seizures and involuntary vocal tics, were given a diagnosis of collective hysteria. The authors highlight that old-fashion ideas about adolescent girls, class assumptions, and social

imaginaries about people from the rural periphery worked together to legitimate the diagnosis.

In Denmark and Japan, girls claiming HPV vaccine injuries received a diagnosis of Chronic Fatigue Syndrome and Postural Orthostatic Tachycardia Syndrome. The narratives of girls and their parents in the UK, attributing adverse events to vaccination with Cervarix, carry echoes of the suspicion and mistrust evoked by the story of El Carmen de Bolívar (Hanbury, 2017). However, in the UK, there were neither diagnoses of collective hysteria nor accusations of symptoms having been faked in the hope of monetary gain. In Colombia, the diagnosis of MPI appeared justified by the “difficult socio-economic background” of the families, the violent history of the region, and the cohesiveness of its communities. In the void left by diagnostic uncertainty, sex, age, and class coalesced with race and locale in evoking and legitimating an image of these subjects.

6.3. The stakes: a dependent epistemic field

Girls’ personal accounts were not regarded as ‘data’ at all, and no attempt was made to collect them. “The outbreak description cannot be done on the basis of anecdotal elements. You cannot interview patients because they will have memory bias, they will not remember what happened,” one health professional explained. Epidemiologists are trained to rely on a hierarchy of evidence, at the pinnacle of which stand randomized controlled trials. Other forms of evidence, especially when collected retrospectively and still more so when reliant on patients’ memories, are suspect (Krieger, 2001). Health policy analysts have argued for policy-making based on a corresponding hierarchy of evidence (Dobrow et al., 2004). Despite the critique of social scientists (e.g. May 2006), this view has gained widespread acceptance among policymakers. If epidemiologists had presented them with an analysis drawing significantly on the girls’ accounts, policymakers would have been inclined to regard it skeptically. The epidemiologists were surely aware of this and of the risk to perceptions of their competence.

The hierarchy of evidence referred to above influences responses to subject experiences in more ways than one. Commitments to certain forms of evidence, to certain ways of making health policy, to conformity with global consensus evoked what might be called a ‘cascade of reluctance’ in the face of the families’ attempts to link the girls’ suffering to the vaccine. The Colombian epidemiologists limited themselves to the kind of data with which they were familiar and which they trusted (Maldonado, 2019). In addition to the loyalty of epidemiologists to the classic tools and protocols of public health, power dynamics between national and international researchers are also at play. “The World Health Organization has never confirmed any link between the vaccine and autoimmune illness”, the director of the National Immunization Program affirmed, defending the vaccine’s safety (El Tiempo, 2016). Following Latour’s analysis of how professional networks mediate expert knowledge and practices, Behague et al. (2009) illuminate the tensions and drives that shape evidence-based policymaking. In the effort to accomplish a homogeneous and coherent ‘voice for science’, scientific values are negotiated between national and international actors, but local studies typically lack influence when their implications differ from those of ‘global studies’ (ibid.). The polemics which developed around the 2018 IETS literature review provide further insights into tensions both around forms of evidence and the relative significance of global and local studies. Critics of the IETS literature review argued that its nuanced conclusions resulted from its having included observational and analytical studies instead of only rigorous experimental ones (Wiesner et al., 2018). The result was that its conclusions clashed with a review published by the Cochrane Collaboration, which included only randomized trials, and which concluded that the vaccine was safe (Arbyn et al., 2018). Given that, the IETS professionals were then asked to reconsider their analysis and review their report. Intriguingly, two months later, Cochrane published an editorial nuancing the conclusions of the previous review, confirming that “[s]ome questions cannot be

answered by this review” (Morrison and Lasserson, 2018, p. 2), including questions about very rare side effects (*ibid.*). Finally, if the government had accepted that the vaccine could cause serious side effects, it would undoubtedly have faced claims for financial compensation. Beyond this, it would have faced a serious dilemma. Should the vaccine be withdrawn or not? How could its withdrawal be justified, not only to the Colombian medical community, which largely believes in it, but internationally? Moreover, what political consequences would this have had? A leading Colombian immunologist, who claims that Gardasil might trigger autoimmune diseases, has pointed out how politically sensitive the issue is (El Tiempo, 2016).

7. Conclusions

Most vaccines have side effects, though they are generally mild and short-lived. Occasionally reports emerge of more serious adverse reactions following vaccination. A few countries have established systems for gathering and investigating such reports. Scientific studies should then establish whether the reactions reported were due to the vaccine and should therefore be acknowledged as ‘vaccine side effects’. Our focus in this paper has been on the controversy that followed immunization against HPV in Colombia, in 2014–2015, and the processes involved in the assessment of unexpected symptoms. We analyzed how the girls in this Caribbean community experienced HPV vaccination and on how their responses to the vaccine were interpreted and processed by the Colombian health bureaucracy. The girls’ claims and their subjective experiences have been neglected, with reliance on hospital records alone. Without recourse to their personal testimonies, the girls of El Carmen de Bolívar were diagnosed as suffering from Mass Psychogenic Illness (MPI). Their attribution of their symptoms and their suffering to the vaccine was rejected. The locus of the problem was thereby shifted from the complainant to the complainant. We have argued that making sense of this shift is possible only in the light of social and historical processes, of the girls’ gender, age and class, and of the lack of biomedical markers corresponding to the symptoms of which they complained. Faced with the lack of any clear diagnostic label, health professionals turned elsewhere in search of an explanation. It has been suggested that societal anxieties become “facts in moments of ambiguity” (Jones, 2010, p. 278, quoted in Goldstein and Hall, 2015, p. 644). Similarly here, as professionals sought to fill the explanatory gap. In reaching the MPI diagnosis, the Colombian authorities drew on societal imaginaries about girls and young women, as well as of this distant, impoverished and marginal community. Their response reflected commitment to a very restricted notion of evidence, as well as an inability or unwillingness to stand against ‘global consensus’.

In conclusion, the controversy around the HPV vaccine that emerged in Colombia, as well as the outcomes of controversies around other vaccines, including Rotashield and Pandemrix, show that what is presented as a rational and logical process of scientific verification is in practice both cognitively and socially far more complex. Acknowledged ‘side effects’ are a resultant of interactions between biological, political, social, economic and historical processes. Nevertheless, transparent and trusted monitoring systems to which unexpected post-vaccination experiences can be reported are crucial to ensuring vaccine safety. We believe they also have a role in enhancing vaccine confidence.

Conflict of interest disclosure

The authors declare no conflict of interests.

Ethics approval statement

Ethical approval was provided through the normal procedures of the Amsterdam Institute for Social Science Research.

Patient consent statement

All interviewees gave their consent by signing a consent form.

Authors contribution

Maurizia Mezza: Conceptualization; Investigation and data collection; writing original draft. Stuart Blume: Formulation; Supervision; Writing-review and editing.

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