

# **Understanding Vaccine Hesitancy and Under-Immunization with Childhood and Human Papillomavirus Vaccines in Switzerland: A Qualitative Study**

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# Understanding Vaccine Hesitancy and Under-Immunization with Childhood and Human Papilloma Virus Vaccines in Switzerland: A Qualitative Study

PhD thesis in the Faculty of Medicine:  
Epidemiology/public health including insurance medicine

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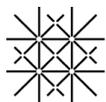
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## Abstract

Extensive biomedical evidence documents the efficacy, minimal unwanted effects, and cost-effectiveness of vaccines recommended by numerous national immunization programs. Despite the public health successes of vaccines, people in high-income countries are expressing concerns about vaccine safety, efficacy or need, a phenomenon referred to as *vaccine hesitancy*. Existing literature points to differing influences on vaccine hesitancy and may include people's personal, social, and local cultural networks, medical providers' attitudes and communicative styles, and complementary and alternative approaches to medicine. Previous literature examining often-used variables in public health literature regarding vaccine hesitancy, such as socioeconomic status (SES) and educational attainment, shows inconsistent correlations between these variables and vaccination attitudes and practices, underscoring the necessity of examining vaccine hesitancy within specific, localized contexts and with attention paid to the decision-making processes. Further complicating the issue, certain parents have been questioning standard vaccination recommendations and instead opting for individualized vaccination schedules. Current scientific literature tends to focus primarily upon interactions between patients and biomedical healthcare providers and does not adequately examine complementary and alternative medical (CAM) provider approaches regarding vaccination perceptions and practices. Furthermore, little information exists on vaccine hesitancy in Switzerland. In order to fill these research gaps, this research focuses on seeking to better understand vaccine hesitancy related to 1) recommended childhood vaccines and 2) human papillomavirus (HPV) vaccines.

This research benefits from a guiding theoretical framework rooted in an *agency-structure approach*, which allows us to underscore the social processes behind vaccine decision-making, including the concepts of the *coproduction of knowledge* and *health literacy*. Coproduction of knowledge refers to the social processes by which social actors come to make and interpret meanings about the world in which they live. Health literacy refers to the socially situated practices through which people access, understand, appraise, and apply health knowledge in order to make health-related decisions.

This research employs qualitative methods in the German and French-speaking parts of Switzerland, including: 1) qualitative face-to-face interviews with parents and healthcare providers and 2) observations of medical consultations between parents and providers. The results from both linguistic regions are compared regarding vaccine knowledge and practices among Swiss parents and medical providers. Particular attention in this study is attributed to the coproduction of knowledge in interactions between complementary and alternative medical (CAM) providers, biomedical providers, and parents.



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# Chapter 1

## Introduction and background

### 1.1 Vaccine hesitancy and under-immunization

Vaccines are ranked among the greatest public health achievements (CDC, 1999). Extensive biomedical evidence documents the efficacy, minimal unwanted effects, and cost-effectiveness of vaccines recommended by numerous national immunization programs, including that of the Swiss Federal Office of Public Health (FOPH) (Maglione et al., 2014; Thompson & Lewis Odahowski, 2014). Despite vaccination implementation successes from a public health perspective, people in high-income countries are expressing concerns about vaccine safety, efficacy or need, a perspective now referred to as *vaccine hesitancy* (Larson et al., 2014; Salmon et al., 2015). That being said, vaccine hesitancy is not a new phenomenon; widespread smallpox inoculation and vaccination efforts were originally met with intense social opposition from their beginnings in the 18<sup>th</sup> century (Riedel, 2005).

Under-immunization is a major public health concern because it reduces population herd immunity towards potentially dangerous infectious agents and increases the risk of disease outbreaks. It also threatens the goal stated by the World Health Organization (WHO) and the FOPH of eliminating measles in the near future. Vaccine hesitancy is a term with variable definitions, with previous research presenting vaccine hesitancy as a set of beliefs, attitudes, or behaviors which influence vaccine-related decisions and outcomes (Peretti-Watel et al., 2015). However, in line with the approach proposed by Peretti et al. (2015), vaccine hesitancy will here be discussed as a socially inscribed decision-making process. Vaccine hesitancy is clearly of increasing international importance, and is by now of such concern that it prompted a press release by WHO in August 2015, in which it was referred to it as a “growing challenge for immunization programmes” (WHO, 2015), and a call to action by the WHO Strategic Advisory Group of Experts on immunization (SAGE) group (Eskola et al., 2015; Larson et al., 2015).

The FOPH measures Swiss vaccination rates at regular intervals, with limited demographic and socioeconomic information being captured. However, this is no longer considered sufficient; the WHO SAGE group now recognizes a “strong need to increase understanding of vaccine hesitancy, its determinants, and the rapidly changing nature of the challenges that this hesitancy entails” (Eskola et al., 2015).

At the *national* level, vaccination coverage in Switzerland overall is high (FOPH, 2015b). Vaccine hesitancy, however, seems to be specific for certain population *subgroups* (Larson et al., 2015). For example, in Switzerland, measles cases, small epidemics, and under-immunization have been shown to cluster around alternative, anthroposophical schools (i.e. Waldorf schools) and around certain providers of complementary and alternative medicine (CAM) (Richard & Masserey Spicher, 2009). Available information on vaccine hesitancy in Switzerland is limited. There is nonetheless data that suggests regional variations in vaccination rates, with trends showing higher rates of vaccination for children in the Italian and French-speaking cantons than in the German-speaking cantons (Lang et al., 2011). In an exploratory qualitative study commissioned by the FOPH, semi-structured interviews were done in a convenience sample of 30 Swiss persons “with potential criticisms against vaccination” (FOPH, 2014). Participants’ verbally expressed vaccine hesitancy was not linked to their vaccination decisions, and the time that had elapsed since the last vaccination decision was not reported. In 2014 the FOPH commissioned a telephone survey regarding attitudes towards vaccination among 1,200 randomly selected Swiss residents aged 15-74 years but was unable to reach any meaningful conclusions due to a limited number of respondents stating they were hesitant (FOPH, 2013).

In another survey commissioned by the FOPH in 2012, 3,237 telephone interviews among a representative sample of young adults and parents of young children living in Switzerland were done, of whom 72% provided a copy of the vaccination booklet of their child and/or themselves respectively. Approximately 7% of children were not vaccinated and 12% were vaccinated later than recommended by FOPH (FOPH, 2015a). Importantly, 25% of parents who vaccinated their child in a delayed fashion reported that the physician recommended delayed vaccinations. This study was repeated in 2015 in

young adults in order to evaluate the Swiss National Measles Elimination strategy and shows that knowledge and beliefs are important aspects to consider in non-vaccination decisions (FOPH, 2016).

Cantonal coverage levels for HPV vaccination range from 79% (Valais) to 19% (Appenzell Innerhoden) for 2 doses of HPV vaccine. HPV coverage estimates only include 16-year-old girls, and estimates for boys are not yet available (FOPH, 2018). The most common reasons for females not being vaccinated against HPV, according to a 2014 survey, included being too old, lack of information, fear of side effects, being against vaccination in general or against HPV vaccination only, HPV vaccination felt to be unnecessary, and simple logistical issues (FOPH, 2015a), with 7% and 6% of women not vaccinated against HPV reporting that the physician or friends/family recommended against HPV vaccine, respectively. Further research has shown that living in cantons with school-based vaccination increases uptake of HPV vaccination (Riesen et al., 2017; Riesen et al., 2018). However, spatial variation modelling has shown that variables such as political opinion, religion, and community opinion might be additional determinative factors in the presence of school-based vaccination programs (Riesen et al., 2018). This suggests further research is needed to better understand vaccine hesitancy and school-based vaccination programs in Switzerland.

### 1.1.1 Definitions: Vaccine hesitancy and under-immunization

- a. *Vaccine hesitancy*, for the purposes of the qualitative components of this research, is defined based upon the verbally or textually expressed concerns about vaccine safety, efficacy, or need during interviews, medical consultation observations, or in external sources. Vaccine hesitancy may also be expressed in terms of providers, parents, and patients who question standard vaccine schedule recommendations and instead show interest for, and perhaps opt for, personalized vaccine schedules for their patients, themselves, or their children.
- b. *Under-immunization* is defined as a function of age, with the official Swiss vaccination recommendations as the reference, and taking into account changes to the recommendations over the years (e.g. HPV reduction from 3 to 2 doses). By recording all administered vaccines and date of their administration based upon participants' vaccination booklets, are able to assess under-immunization (omitted or delayed vaccines) for each individual vaccine of interest.

### 1.1.2 Underpinnings of vaccine hesitancy

Studies outside of the Swiss context suggest that personal, social (Brunson, 2013; Poland & Brunson, 2015) and local cultural (Peretti-Watel et al., 2015) networks are important factors to consider when it comes to vaccination decisions, in particular for people who under-vaccinate. It is important to note that often-used quantitative variables in public health research, such as socioeconomic status (SES) and educational attainment, provide inconsistent results when correlated with vaccine outcomes (Peretti-Watel et al., 2015). As an example, Reich (2016) notes those who choose not to vaccinate their children by choice in the United States tend to be college-educated, upper-middle class, white mothers whereas parents who do not vaccinate their children due to a lack of resources tend to be unmarried, black mothers without a college education who rely upon publicly funded healthcare (Reich, 2016b). In both instances, children's vaccination outcomes are the same, but the children come from families with different socioeconomic profiles, and the reasons behind their under-immunization differ. Reich (2016) also notes how more privileged families are better equipped to deal with children's infections that vaccinations could have otherwise prevented, which is something these families may consider in their vaccination decisions. Other studies have found similarly differentiated, and puzzlingly inconsistent, relationships between SES, educational attainment, and vaccine outcomes in other contexts (North American, European, African, and Asian), which underscores the need to examine vaccine hesitancy within specific, localized contexts (Larson et al., 2014). In light of these discussions, researchers highlight the need to clearly distinguish between (1) under-immunization as it relates to questions of access, affordability, logistics, and inadequate health systems, and (2) under-immunization as it relates to varying degrees of vaccine acceptance and non-acceptance (Bedford et al., 2018).

A key factor for vaccination uptake seems to be the attitudes and behavior of the provider, with providers who are trusted by their patients being more likely to successfully recommend vaccinations (Salmon et al., 2008; Opel et al., 2013; Verger et al., 2015). The literature cites insufficient time, materials, and knowledge as constraints for providers' ability to sufficiently convey information about vaccinations to their patients (Davis et al., 2001; Kimmel et al., 2003). Additionally, the literature shows that providers' communication styles during discussions with patients can play determining roles in

convincing, or not, parents to vaccinate their children (Bryant et al., 2009; Opel et al., 2012; Opel et al., 2013). One such study found that providers who use a participatory approach to vaccinations (i.e. “What do you think about vaccinating your children?”), as opposed to a presumptive approach (i.e. “We are going to do some vaccinations today.”), were more likely to be met with expressed vaccine hesitancy during the patient-provider interaction (Opel et al., 2013). However, the same study showed that providers who persisted with their original recommendations were more likely to be successful in convincing parents to vaccinate their children despite their originally expressed vaccine hesitancy.

The literature highlights the importance of paying closer attention to patient-provider interactions during the parents’ vaccination decision-making process, as these encounters can play a crucial role in determining vaccine outcomes. To our knowledge, patient-provider interactions during discussions on vaccinations have only been observed and studied with biomedical<sup>1</sup> providers, and complementary and alternative medical (CAM) providers’ interactions with their patients remain understudied regarding vaccination decisions. A notable exception includes qualitative interviews conducted by Attwell et al. (2018) with parents in Australia; researchers describe how parents and CAM providers exemplified a *symbiotic* relationship, explaining, “Vaccine hesitancy and CAM exist and function separately, but when combined, provide each other with ‘resources’ that enable them to thrive together” (p. 111). This gap in the literature necessitates an approach that compares vaccine consultations between CAM and biomedical providers and their patients.

Alternative parent and provider perspectives need to be considered in order to understand vaccine hesitancy (Poland & Brunson, 2015). These perspectives may include an intuitive rather than analytical cognitive style, reluctance to consider the evidence suggesting vaccine safety/efficacy, and lowered willingness to trust information delivered by biomedical authority sources, as shown in an adherence to CAM oriented health values and preference/utilization of CAM over biomedical treatments (Browne et al., 2015). Studies highlight that vaccine hesitancy and CAM use are influenced by similar factors, such as alternative concepts of body, immunity, risk perception, anti-authoritarian orientation, and distrust towards biomedical institutions and/or the pharmaceutical industry (FOPH, 2009; Browne et al., 2015; Peretti-Watel et al., 2015). These findings suggest major limitations to the efficacy of evidence-based, biomedical strategies that aim at increasing vaccination rates (Browne et al., 2015).

In light of the above-mentioned literature, this study focuses on the processes through which parents and providers consider, understand, and coproduce knowledge related to vaccines and how this knowledge influences vaccination-related decisions. This perspective is further addressed by the study design, which allowed us to gain insight into patient-provider interactions regarding vaccination decisions.

### 1.1.3 Focus on childhood and HPV vaccines

This research focused on childhood vaccines because results of the National Vaccination Coverage Survey shows lower vaccination coverage for measles than other vaccines (e.g. tetanus) (FOPH, 2013) and because measles and pertussis cause significant morbidity. Additionally, Switzerland did not meet the WHO’s goal of eliminating measles by 2015 (WHO, 2010) and even witnessed large epidemics of measles between November 2006 and August 2009. During these epidemics, Switzerland experienced by far the highest measles incidence rates in Europe, with rates of 15 per 100,000 in 2007 and 29 per 100,000 in 2008 (Richard & Masserey Spicher, 2009). Furthermore, the World Health Organization listed vaccine hesitancy among 10 “threats to global health” in 2019, citing a 30% increase of measles globally (WHO, 2019). Switzerland was not immune to these increases in measles, with 212 reported cases as of October 8, 2019, which represented more than 6 times as many cases as for the same period in 2018 (FOPH, 2019). Such outbreaks call attention to the importance of understanding why parents choose not to provide childhood vaccinations for their children for diseases that could otherwise be prevented.

The second focus on the HPV vaccine comes from evidence showing that hesitancy towards the HPV vaccine is high and that under-immunization is more common for HPV when compared to other vaccines. Both the CDC and WHO recognize the potential of HPV vaccines to prevent the development of cervical, anogenital, and some head and neck cancers and genital warts caused by

<sup>1</sup> Various terms are in use to refer to “conventional,” “mainstream,” or “allopathic” medical and public health approaches to medicine. The term “biomedical” is used throughout the thesis.

an HPV infection (Meites et al., 2016). A 2017 WHO position paper recommends HPV vaccination as a priority for the prevention of cervical cancer for females aged 9-14 years prior to them becoming sexually active (WHO, 2017). The same report recognizes the HPV vaccination for secondary target populations (i.e. for males, or for females over the age of 15) and alludes to public health ambivalence towards perspectives on the cost-benefit calculation of vaccinating both males and females between countries. In Switzerland, the FOPH recommends the HPV vaccine for all adolescents between the ages of 11 and 14, with the HPV vaccine being a recommended *essential* vaccine<sup>2</sup> for females and an *additional* vaccine for males (FOPH, 2017).

Low HPV vaccine uptake rates are in part likely due to parental hesitancy towards the vaccination (Patel & Berenson, 2013). However, parental hesitancy towards HPV vaccines is not due, as HPV vaccine opponents tend to argue, to the vaccine's ability to prevent sexually transmitted infections, which could, along this line of argument, potentially encourage teenage sexual activity (Patel & Berenson, 2013). A systematic review of HPV acceptability in the United States showed that a minority of HPV resistant parents feel this way, whereas, depending on the study examined, between 55 and 100% of parents were willing to vaccinate their children against HPV, and acceptability of the HPV vaccine depended upon perceived likelihood of contracting HPV, perceived severity of HPV infections, perceived effectiveness of the vaccine, and physicians' recommendations of the vaccine (Brewer & Fazekas, 2007). Evidence does however show that parents who do vaccinate against HPV tend to do so in later years of adolescence, which is when the HPV vaccine may have less of an impact, especially if adolescents have already engaged in sexual activities (Roberts et al., 2015). Studies on HPV vaccine hesitancy will benefit from closer attention to decision-making processes and rationale behind parents' decisions regarding this vaccine.

## 1.2 Theoretical framework

In order to address the gaps in the scientific literature regarding vaccine hesitancy and under-immunization, I benefited from a guiding theoretical framework with the aim of better understanding the processes behind this complex, multifaceted phenomenon. This project borrows from theoretically relevant literature dealing with the *coproduction of health and medical knowledge*, which is understood as being contingent upon social interaction and as involving various types of knowledge (medical, evidence-based, experiential, and lay). The discussions concerning the coproduction of knowledge in regard to vaccination are subsequently linked to the concept of *health literacy*, a term that has been gaining traction and growing in relevance in recent years in public health literature. Finally, these concepts are integrated into an agency-structure approach, which is useful for understanding the social processes which shape vaccine hesitancy and under-immunization in Switzerland.

### 1.2.1 Knowledge production and health literacy

This research cannot be conducted without placing vaccine hesitancy and under-immunization against the backdrop of larger social trends regarding the changes in healthcare decisions and practices that have been taking place over the last several decades. These social trends often have complex theoretical underpinnings and have to do with meaning making processes, the questioning of the validity of claims and truth(s), and knowledge-making processes related to science, medicine, and society. In other words, in the context of *postmodern medicine* (Gray, 1999), people, patients, and doctors concurrently negotiate and renegotiate differing knowledges and truths while making healthcare decisions. In postmodern contexts of truth and knowledge, science is increasingly called into question and viewed with higher levels of skepticism. Muir Gray (1999) explains these phenomena by highlighting questions of importance related to: 1) citizens' concerns with social values as well as evidence in making healthcare decisions, 2) a preoccupation with risk rather than benefit, and 3) the rise of the well-informed patient (p. 1551). Other authors highlight a heightened skepticism towards biomedical knowledge as being due, in part, to more attention that consumers and patients pay to the influence of ideology and perceived outside financial interests in scientific production processes, the economic interests of the pharmaceutical industry, organizational dysfunction in public

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<sup>2</sup> The BAG/OFSP designates three classifications of vaccinations in Switzerland: 1) recommended essential vaccinations, 2) additional vaccinations, and 3) vaccinations destined for at-risk groups and vulnerable populations. The HPV vaccine is considered as a recommended essential vaccine for females aged 11 to 14 and thus reimbursed by medical insurance. The HPV vaccine is considered as an additional vaccine for males and is consequently not reimbursed by medical insurance.

health systems, and the availability of a multitude of, sometimes contradictory, sources of information and recommendations, even from biomedical experts (Epstein, 1996; Yaqub et al., 2014; Jiang & Beaudoin, 2016; Reich, 2016a). A main shift has been that patients, rather than simply accepting medical providers' expertise and recommendations, have become more empowered and assertive in making their health-related decisions, even if these decisions differ from biomedical recommendations (Gray, 1999; Armstrong, 2014; Reich, 2016a). An example of this would be patients, parents, and providers opting for individualized vaccine schedules instead of following recommended standard vaccine schedules, leading to under-immunization. Notably, the empowerment approach to healthcare aligns with WHO's 1986 commissioned *Ottawa Charter's* (WHO, 1986) encouragement for a heightened level of individuals' control over their healthcare decisions and health improvement.

Coupled with the growing skepticism towards biomedical institutions, pharmaceutical companies, and scientific expertise, patients, consumers, and practitioners have been showing growing interest for complementary and alternative medicine<sup>3</sup> (CAM) (Ernst & Fugh-Berman, 2002). Gale (2014) cites the literature review of Siahpush (2000) to explain the growing utilization of CAM as being a result of:

(...) dissatisfaction with the health outcomes of orthodox medicine; dissatisfaction with the medical encounter/doctor-patient relationship; preference for the way alternative therapists treated their patients, including being caring, individualized attention, ample time and information; the emergence of a new philosophy around nature and holism related to a postmodern value system; the heterogeneity of an individual's social network, resulting in exposure to a wider range of information and values; and finally, that alternative therapies fulfilled a psychological need in the wake of the waning of organized religion, providing an alternative framework for making sense of illness, suffering, and misfortune (p. 807).

Interest for CAM has also been evidenced in Switzerland. A review of the relevant literature on the prevalence of CAM use in Switzerland concluded that about 50% of the Swiss population utilizes CAM, a large majority of which appreciates it and finds it to be effective, about 50% of physicians consider CAM to be effective, and more than half of the population have preference for treatment in a CAM hospital and would like to have CAM coverage with their private health insurance (Wolf et al., 2005). The utilization of CAM and its relationship to parental vaccination decisions is something that merits further study (Salmon et al., 2008; Browne et al., 2015; Peretti-Watel et al., 2015), particularly in Switzerland where these questions have not been adequately addressed. That said, outside of the Swiss context, other researchers have found a significant association between parental CAM use and lower rates of adherence to recommended pediatric vaccination schedules in the state of Washington (Downey et al., 2010).

The complexity of the theoretical underpinnings specific to the growing skepticism towards biomedical approaches to medicine comes from the difficulty of explaining how different iterations and versions of scientific truth and knowledge have come to present themselves in postmodern contexts. For this, social scientists, particularly those working in the field of science and technology studies (STS), have researched how scientific "facts" come to be perceived as such and view scientific fact production as a social process (Popper, 1959; Latour & Woolgar, 1979; Vinck, 2007). Jasanoff (2006) explains how scientific knowledge is intertwined with social realities: "Scientific knowledge, in particular, is not a transcendent mirror of reality. It both embeds and is embedded in social practices, identities, norms, conventions, discourses, instruments and institutions – in short, in all the building blocks of what we term the *social*." (p. 3, emphasis in original). Gibbons et al. (1994) present theoretical considerations on the subject and present two modes of *knowledge production*: Mode 1, or *traditional knowledge*, in which knowledge is "generated within a disciplinary, primarily cognitive, context", and Mode 2 knowledge, which is "created in broader, transdisciplinary social and economic contexts" (p.1). Gibbons and colleagues further explain the defining characteristics of and differences between knowledge produced within Modes 1 and Mode 2:

(...) in Mode 1 problems are set and solved in a context governed by the, largely academic, interests of a specific community. By contrast, Mode 2 knowledge is carried out in a context of application. Mode 1 is disciplinary while Mode 2 is

<sup>3</sup> For a more detailed discussion on the differences in terminology between *traditional medicine* (TM), *biomedicine*, and *complementary and alternative medicine*, and the political and power implications of this usage, see Gale (2014).

transdisciplinary. Mode 1 is characterized by homogeneity, Mode 2 by heterogeneity. Organisationally, Mode 1 is hierarchical and tends to preserve its form, while Mode 2 is more heterarchical and transient. (...) In comparison with Mode 1, Mode 2 is more socially accountable and reflexive. It includes a wider, more temporary and heterogeneous set of practitioners, collaborating on a problem defined in a specific and localised context (p. 3).

In line with Gibbons, I argue that the focus of this research should be on *knowledge* that is coproduced in Mode 2, as health-related knowledge production has been extending outside the disciplinary realms of the biomedical sciences, and vaccine hesitant proponents tend to reject biomedical discourse related to vaccine safety, efficacy, and need. The *coproduction of knowledge* therefore refers to the social processes by which social actors come to make and interpret meanings about the world in which they live. It is also important to consider how coproduced knowledge, once established as such, is then put into practice.

The use of the term *knowledge* in this research does not necessarily indicate evidence-based, scientific discourse. Rather, the use of the term indicates what individuals perceive as being information on which they can base their health-related decisions. Borrowing from STS conceptions, knowledge is understood to be a product of social interactions. Such an understanding of knowledge allows researchers to attribute more weight and serious consideration to knowledge not produced within the confines of the scientific method. This conceptualization takes issue with public health literature's use of terms such as *attitudes* and *beliefs* when discussing health knowledge that contests biomedical knowledge. Medical sociologists view the labeling of alternative knowledges as *attitudes* or *beliefs* as being potentially dismissive of those who do not adhere to biomedical discourse. Perhaps done unintentionally, this stance nonetheless denigrates how actors consider the information and the experiences on which they base their health decisions (Bury, 1997). Furthermore, articulated this way, knowledge involving vaccines can be more broadly understood while considering the multiple iterations of the ways of knowing (medical, evidence-based, experiential, and lay), which ultimately sheds light onto the competing knowledges involved regarding vaccination.

The view of knowledge as a product of social interactions finds roots in the *symbolic interactionism* (SI) tradition of social science research. Blumer (1969) explains how SI rests upon "three simple premises" (p. 2) that aim to explain human behavior : 1) people act towards objects based upon the meanings that they attach to these objects, 2) the meaning attached to objects derives from people's interactions with others, and 3) these meanings are negotiated through an interpretative process used by people as they produce meaning related to objects. Mikulak (2011) shares this perspective in a discussion in which she attempts to better understand the "discursive distance" (p. 202) between *scientific* and *non-scientific cultures*. Framed this way, the SI approach allows researchers to consider the complexities of knowledge production and knowledge communication between experts and lay people by paying particular attention to the coproduction of knowledge and meaning making processes involved therein.

Within such a framework, knowledge production in both Modes 1 and Mode 2 related to vaccines occurs as a process negotiated by various actors as they make and interpret meanings related to vaccinations. Within Mode 1, the knowledge production processes take place within the framework of the scientific method. Within Mode 2, knowledge production processes are more flexible and are more malleable to and contingent upon social interactions. It is therefore beneficial to explore how vaccine knowledge is produced within Mode 2 and then subsequently put into practice. Additionally, this research will particularly focus on how various social actors (parents, health providers, and information sources) seek and produce knowledge, the significance they attribute to this knowledge, and how this coproduced knowledge then comes to affect change in vaccine-related practices. This research seeks to understand how different knowledges regarding vaccination are embedded and articulated within social interactions.

In addition to paying particular attention to the coproduction of knowledge related to vaccines in Switzerland, this project benefits from tying these discussions to the concept of *health literacy*. Due to a lack of a unanimously accepted definition among public health researchers for the term, Sørensen et al. (2012) carried out a systematic review of the literature in order to develop a collaborative, comprehensive, and integrative definition. As a result of their review, they propose the following definition:

Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (p. 3)

They elaborate by bridging the problematic gap that they saw in the literature between 1) individual approaches to health and 2) health literacy from a public health perspective: "This definition (...) can easily be specified to accommodate an individual approach by substituting the three domains of health 'healthcare, disease prevention and health promotion' with 'being ill, being at risk and staying healthy'" (p. 3). The researchers insist upon several items that should be kept in mind when conceptualizing health literacy: 1) there exist many different types of literacy, and this should be taken into account when *literacy* as a concept is mentioned and operationalized (i.e. media literacy, fundamental literacy, science literacy, civic literacy, and cultural literacy), 2) "health literacy is also a process, which involves the consecutive steps of accessing, understanding, processing and communicating information" (p. 8) and this process is not static, as health literacy develops throughout the life course, 3) empirical work needs to be carried out in order to find the mechanisms and correlations between health literacy *antecedents* (demographic factors, cultural factors, general literacy, socioeconomic status, age, race, gender, etc.) and health literacy's consequences and outcomes, 4) it is becoming a commonly accepted and recognized goal to augment health literacy, as a determinant of health, in order to improve public health, and 5) new tools and measurements, which must include a comprehensive definition and conceptual understanding of *health literacy*, are required in the fields of social science and public health in order to measure health literacy among populations.

Papen (2009) argues similarly in advancing a social practices view on health literacy, which underscores health literacy's social embeddedness, processuality, and its contextual nature as taking place between multiple actors: "health literacy needs to be understood as a situated social practice and (...) a shared resource frequently achieved collectively by groups of people" (p. 19). Papen's approach takes issue with the dominant view of health literacy as an individualized skill that can be quantified through performance measurements. A social practices view on health literacy instead moves past this limited cognitive view of health literacy and considers social actors' social contexts, the emotional aspects of health, available resources, and the processes through which individuals access and make sense of health information.

Given these reflections, it is pertinent to question the development of health literacy within contexts where coproduced knowledge serves as an alternative to expert medical knowledge, especially regarding knowledge that may increase vaccine hesitancy. In other words, the literature on vaccine hesitancy and under-immunization practices will benefit from attention to the processes through which individuals and collectives come to produce, implement, and change knowledge related to vaccines. This is particularly beneficial from a public health perspective, as health knowledge that is advanced by vaccine hesitant individuals and collectives call into question the legitimacy and credibility of biomedical information pertaining to vaccines.

### 1.2.2 Vaccine hesitancy within an agency-structure framework

Much of the previous public health literature on the subject of vaccine hesitancy and under-immunization has tended to view parents who under-immunize their children, providers who discourage vaccinations, and sources that discourage vaccine practices by inciting vaccine skepticism as obstacles to the improvement of health from a public perspective and as barriers to disease prevention (Poland & Jacobson, 2001; Poltorak et al., 2005; Davis & Shah, 2009; Sadaf et al., 2013; Williams & Swan, 2014). Previous literature has also tended to gloss over hesitant providers', parents', and sources' roles as active and engaged actors in decision-making processes regarding vaccination. The literature has additionally tended to see these actors as passive recipients, with fixed attitudes, beliefs, and perspectives on vaccinations, and as beneficiaries of potential medicalized vaccine intervention implementation programs that aim at increasing evidence-based awareness surrounding the benefits and effectiveness of vaccinations. However, these perspectives have been changing in the literature, with researchers having acknowledged the growing need to better understand the processes through which individuals make vaccination-related decisions, with an emphasis on the necessity to view decision-making in its processual aspects with localized

specificities (Poland & Jacobson, 2001; Poltorak et al., 2005; Larson et al., 2014; Peretti-Watel et al., 2015; Poland & Brunson, 2015).

Furthermore, current literature tends to consider vaccination without seriously taking into account larger trends shaping current medical landscapes of postmodern medicine, where scientific knowledge and medical institutions are increasingly contested. As Reich (2016a) notes, “Parents make their vaccine decisions based on the degree to which they trust the systems responsible for vaccines” (p. 137). The perceived mistrust and lack of credibility in institutions involved with vaccination is a key issue that needs to be addressed, especially if the public health goal is to counter vaccine-skeptical knowledge in order to increase rates of vaccination at a population level (Epstein, 1996; Salmon et al., 2015). As Yaqub et al. (2014) point out, “the credibility of institutions seems to matter more than the information content itself” (p. 7) when it comes to parents’ attitudes and beliefs towards vaccine knowledge. These researchers’ understandings of institutional (mis)trust underscore the need to better understand the processes and the contexts through which people come to generate and discuss knowledge that people do actually trust, as well as the larger institutions where scientific knowledge is produced, when making vaccination decisions.

The literature on this topic benefits from a combination of public health, individual medical provider, and social science perspectives that engage the discussion of vaccine hesitancy and under-immunization, the coproduction of knowledge, and health literacy with questions of *agency* and *structure* as they specifically relate to vaccine hesitancy. This approach recognizes the capabilities for action of social actors (*agency*) to become empowered to interact with the governing *structures* related to health (medical institutions, social networks, norms, and beliefs) in order to seek more favorable health outcomes for themselves<sup>4</sup>. As such, this research seeks to establish how relevant actors (parents, biomedical and CAM providers, and sources of information related to vaccines) interact and negotiate with relevant structures (medical institutions, social networks, norms, and beliefs) in making vaccination-related decisions and in interacting with, and potentially modifying, vaccine knowledge. The structure-agency approach pays attention to what these practices are, who the social actors are that are conducting them, and to the social structures framing these actions. Such an approach additionally considers the meanings that these actors create and attach to these actions. The agency-structure perspective allows us to consider one of the research’s main areas of focus (patient-provider interactions regarding vaccination decisions), while at the same time allowing us to consider other influences on vaccination decision-making that are external to patient-provider interactions.

Considering vaccine hesitant individuals and collectives as empowered within this agency-structure discussion sheds light onto potential criticisms of the Ottawa Charter’s (WHO, 1986) goals of promoting public health by encouraging people to take control of their health in order to improve it. In other words, empowering individuals to have higher levels of control over their healthcare decisions in order to improve their overall health may actually be counterintuitive and even have undesired consequences from a public health perspective when it comes to vaccines. Additionally, this discussion underscores a tension between the promotion of individualized healthcare decisions and public health outcomes when these individual level decisions can impact the social environment in terms of infectious disease prevention within communities. Therefore, a critical approach is necessary and underscores the need to pay closer attention to the processes through which individuals coproduce knowledge and health literacy during vaccination decision-making. This framework highlights how social actors (parents, biomedical and CAM providers, and sources of vaccine information) interact to produce knowledge and make decisions, especially as these actors navigate the overarching structures (medical institutions, social networks, norms, and beliefs) while coming to their vaccine-related decisions. This approach does not view the actors and/or structures as deterministic of vaccine-related outcomes, but rather considers them as co-constitutive and thus susceptible to potential changes from a public health perspective. In other words, the agency-structure approach, in its attention to the processes involved in vaccine-related decision-making, leaves room for the potential of public health interventions that would aim to increase vaccine rates at a population level and to counter discourse that incites vaccine hesitancy.

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<sup>4</sup> For a thorough review of the theoretical approaches discussed herein, see *Abel and Frohlich (2011)*.

## 2 Objectives and research

### 2.1 Research objectives

- 1) *to establish the underlying processes by which parents come to make vaccine-related decisions for their children in Switzerland.*
  - This objective benefits from attention paid to the meanings parents attach to vaccine knowledge, the knowledge sources utilized by parents, and to parents' concerns related to vaccines in their decision-making processes. This allows us to explore at what level (individual, family, collective, societal, etc.) their concerns are considered in making vaccine decisions and to examine how these concerns are tied to parent understandings of the body, immunity, infection, and differing approaches to medicine. Parents' social networks, family structures, parenting health practices, and worldviews are also considered. This objective benefits from attention to the actors involved (parents, biomedical and CAM providers, and sources of knowledge, such as the Internet) and how these actors interact with the overarching structures (medical institutions, social networks, norms, and beliefs) governing decision-making processes.
- 2) *to establish how medical providers (both CAM and biomedical) consider what recommendations to provide to their patients regarding vaccinations in Switzerland.*
  - This objective benefits from attention paid to the meanings providers attach to vaccine knowledge, knowledge sources utilized by medical providers, and to providers' consideration of the consequences of vaccination or non-vaccination in their recommendations. This allows us to explore at what level (individual, family, collective, societal, etc.) their concerns are considered as they discuss vaccinations with patients and to examine how these concerns are tied to provider understandings of the body, immunity, infection, and differing approaches to medicine.
- 3) *to analyze the coproduction of knowledge and health literacy development regarding vaccination information and practices in Switzerland during patient-provider interactions.*
  - This objective benefits from attention paid to providers' communicative styles, the amount of time they spend discussing vaccinations with their patients, and how parents utilize the vaccine knowledge discussed during these interactions in order to make vaccination decisions. This objective benefits from including both biomedical and CAM providers in the study design, which allows us to explore vaccine hesitancy's relationships with differing approaches to medicine, prevention, health, illness, and well-being.

### 2.2 Research questions

- 1) How do parents make vaccination-related decisions for their children in Switzerland? How is their vaccination-related knowledge generated and negotiated, and what meanings do they attach to this knowledge? Who and what are parents' sources of vaccine knowledge, and how do parents interact with and interpret these knowledge sources?
- 2) How do medical providers (both CAM and biomedical) consider what recommendations to make to their patients regarding vaccinations in Switzerland? How is their vaccination-related knowledge generated and negotiated, and what meanings do they attach to this knowledge? Who and what are providers' sources of vaccine knowledge, and how do providers utilize these sources in regard to vaccination decisions?
- 3) How do medical providers discuss children's vaccines with parents in Switzerland? How is vaccine knowledge coproduced during these interactions? How do these interactions influence vaccination decisions?

### 2.3 Study context

This PhD project was conducted in conjunction with a Swiss National Science Foundation (SNSF) grant funded through the National Research Program (NRP) 74, "Smarter Health Care." The overall study (Tarr et al.) takes place between 2017 and 2021 and is headed and directly supervised by Prof. Dr. med. Philip Tarr (Co-Chief, University Department of Medicine and Infectious Diseases Service,

Kantonsspital Baselland, University of Basel). Co-applicants for the grant are Prof. Dr. med. Andreas Zeller (Director, Universitäre Zentrum für Hausarztmedizin beider Basel), Prof. Dr. Claudine Burton-Jeangros (Vice Dean of the Faculty of Social Sciences and Professor of Sociology, University of Geneva), and Prof. Dr. med. Christoph Berger (Co-chief, Infectious Diseases, Kinderspital Zürich; President, Federal Vaccination Commission of FOPH). The PhD research does not directly, nor in detail, address the quantitative aspects of the study, which are discussed in detail in the methodology chapter. Focus herein is rather attributed to the qualitative components of the research.

## 2.4 Study relevance

**Scientific significance:** Information regarding the sociocultural, medical, and demographic aspects of vaccine hesitancy and under-immunization in Switzerland is highly limited. This research therefore focuses on major unresolved research questions that, according to WHO, need to be urgently addressed in high-income countries. Results from the study are novel and represent an important contribution to the field. The novelty of the study comes from 1) the involvement of CAM providers and parents who utilize CAM for their children in the study design and 2) the inclusion of both CAM and biomedical providers for medical consultation observations. This approach allows us to include alternative theoretical, parent, and provider perspectives in discussions related to vaccination in Switzerland.

**Socioeconomic significance:** From a biomedical perspective, under-immunization and vaccine hesitancy are striking examples of the underuse of a safe, effective, and cost-effective medical intervention. Since a primary focus of the National Research Programme (NRP 74) relates to the overuse and underuse of medical services, the underuse of vaccines in Switzerland was an important aspect they considered for the funding of this research. Underuse of vaccines appears to be specific to certain sociocultural population subgroups and likely specific to certain vaccines. The research aims at detailed characterization of the personal and sociocultural contexts in which under-immunization is taking place in Switzerland by including French and German-speaking regions. Economic costs of epidemics from a health systems view are substantial, including treatment costs, days off from work due to own illness or care for an ill child, and costs of treatment and loss of productivity due to serious sequelae and even lost disability-adjusted life years due to death, and could be alleviated by high vaccination coverage (Quilici et al., 2015).

## 2.5 Study ethical considerations

Ethical clearance for this research was given by the EKNZ (Ethikkommission Nordwest- und Zentralschweiz) in June 2017 (project ID number 2017–00725). Since there is expected minimal risk for involved study participants, the research team has received approval for ethical clearance within the risk category A. The research project was carried out in accordance to the research plan and with principles enunciated in the "Declaration of Helsinki" (2013), Essentials of Good Epidemiological Practice issued by Public Health Schweiz (EGEP), the Swiss Law, and Swiss regulatory authority's requirement.

## 3 Thesis structure

The chapters that follow were informed by the above-discussed definitions, brief review of relevant literature, and theoretical framework. In Chapter 2, which is a study protocol paper, we have outlined in detail the overall National Research Program 74 research aims, objectives, and methodologies. In Chapter 3, we discuss the practices and perspectives of CAM providers in Switzerland by particularly focusing on the novel qualitative evidence pointing to how they emphasize individualized approaches to vaccination counseling. In Chapter 4, we discuss qualitative evidence concerning biomedical doctors' perceptions of and interactions with vaccine hesitant and under-immunized parents and patients. This chapter sheds light onto the underdiscussed issue of healthcare providers' (HCPs) roles, reputations, and responsibilities in vaccination consultations. In Chapter 5, we describe parents' logics of care in vaccination decision-making at the intersections of their use of CAM and biomedicine. In this chapter, we particularly focus on how parents express (dis)satisfaction in clinical encounters through their provider-selecting practices. In Chapter 6, the conclusion chapter, I revisit the theoretical

framework I have outlined above by tying together the different threads that run throughout the empirical findings and articulating them in relation to current literature on vaccine hesitancy and under-immunization. In the conclusions, I also provide a brief discussion into potential future directions for research into this field by emphasizing the importance of continued social science approaches in interdisciplinary research in health sciences, preventive medicine, health promotion, infectious disease prevention, and public health and epidemiology.

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## Chapter 2

# Methodological Considerations: “Determinants of vaccine hesitancy in Switzerland: study protocol of a mixed-methods national research programme”

### Notes

This article was published in *BMJ Open*. It was submitted on January 11, 2019, submitted in revised form on August 30, 2019, and accepted for publication on September 12, 2019.

For the purposes of the PhD research, the methods reported in the “Qualitative methods” section in the article below are valid for the following chapters. Whereas we were able to retain the overall research study’s focus on routine childhood vaccinations and the human papillomavirus (HPV) vaccine for Chapters 3, 4, and 5, these chapters benefit more from a focus on childhood vaccinations, with several references to the HPV vaccine in each.

The study team recognized that our first round of qualitative data collection raised additional and worthwhile research questions related to HPV vaccination practices, attitudes, and knowledge in the Swiss context. As a result, we are currently undertaking additional qualitative work with youth, parents, schools, and public health officials. This additional research is not reported in the PhD.

Furthermore, since vaccination information sources were collected for both HPV and childhood vaccinations throughout the duration of this study, and vaccination information sources are systematically being documented through the overall study’s quantitative methods, the thematic analysis and critical discourse analysis described in the section “Vaccination information sources” will be conducted after we have completed the additional qualitative research into HPV vaccination and after we have compiled the quantitative resources about vaccination information sources.

# BMJ Open Determinants of vaccine hesitancy in Switzerland: study protocol of a mixed-methods national research programme

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## ABSTRACT

**Introduction** Vaccine hesitancy is a complex public health issue referring to concerns about the safety, efficacy or need for vaccination. Relatively little is known about vaccine hesitancy in Switzerland. This ongoing study (2017–2021) focuses on biomedical and complementary and alternative medicine (CAM) providers and their patients since healthcare professionals play important roles in vaccination decision-making. This national research programme seeks to assess the sociocultural determinants of vaccine hesitancy regarding childhood and human papillomavirus vaccines in Switzerland. We aim to provide a detailed characterisation of vaccine hesitancy, including CAM and biomedical perspectives, patient–provider interactions, and sociocultural factors, to establish the mediating effects of vaccine hesitancy on underimmunisation, and to design an intervention to improve vaccination communication and counselling among physicians, parents and adolescents.

**Methods and analysis** Our transdisciplinary team employs a sequential exploratory mixed-methods study design. We have established a network of more than 150 medical providers across Switzerland, including more than 40 CAM practitioners. For the qualitative component, we conduct interviews with parents, youth, and biomedical and CAM providers and observations of vaccination consultations and school vaccination information sessions. For the quantitative component, a sample of 1350 parents of young children and 722 young adults (15–26 years) and their medical providers respond to questionnaires. We measure vaccine hesitancy with the Parent Attitudes about Childhood Vaccines 15-item survey and review vaccination certificates to assess vaccination status. We administer additional questions based on findings from qualitative research, addressing communication with medical providers, vaccine information sources and perceptions of risk control vis-à-vis vaccine-preventable diseases. The questionnaires capture sociodemographics, political views, religion and spirituality, and moral foundations.

**Ethics and dissemination** The study was approved by the local ethics committee. The results will be published in peer-reviewed journals and disseminated to healthcare professionals, researchers and the public via conferences and public presentations.

## Strengths and limitations of this study

- A novelty of this research includes its large sample of complementary and alternative medicine (CAM) and biomedical providers, with consideration given to their vaccination perspectives and interactions with their patients.
- The study emphasis on CAM providers is important since previous studies have shown an association between CAM use and vaccine hesitancy as well as high patient demand for CAM in Switzerland.
- The sequential exploratory mixed-method study design and transdisciplinary nature of this study provide further insights into the relationships between CAM and biomedical providers and vaccine hesitancy and uptake, with the qualitative methods and results having informed the design of the quantitative questionnaire.
- Although the methodological approach to recruit patients via medical providers is advantageous because it allows for the examination of effects of provider characteristics on patient vaccination beliefs and behaviours, it limits our results because populations that do not regularly see medical providers are under-represented in our data.
- Furthermore, the data do not provide nationally representative results.

## INTRODUCTION

Vaccines are ranked among the greatest public health achievements.<sup>1</sup> Extensive evidence documents the efficacy, minimal side effects and cost-effectiveness of vaccines recommended by numerous national immunisation programmes, including that of the Swiss Federal Office of Public Health (FOPH).<sup>2,3</sup> Despite public health successes of vaccines, a large number of people in Western countries express concerns about vaccine safety, efficacy or need, a behaviour now referred to as *vaccine hesitancy*.<sup>4–6</sup>

Vaccine hesitancy has gained increasing attention from the global public health



community. In August 2015, the WHO referred to vaccine hesitancy as a ‘growing challenge for immunization programs’,<sup>7-9</sup> responding to a 2014 report<sup>10</sup> from the WHO Strategic Advisory Group of Experts on Immunisation. In early 2019, WHO listed vaccine hesitancy among the top 10 threats to global health, citing a global need to address rising rates of measles and to eliminate cervical cancer by ramping up efforts to increase coverage with the human papillomavirus (HPV) vaccine.<sup>11</sup>

While the importance of vaccine hesitancy is widely acknowledged, its determinants are incompletely understood and merit further investigation.<sup>4</sup> Researchers having conducted a systematic review on determinants of vaccine hesitancy from a global perspective found that there was ‘no universal algorithm’ (p2155) and recommended context-specific research.<sup>4</sup> Other researchers have argued in favour of cross-disciplinary research, stating ‘Vaccine hesitancy and acceptance are complex, multi-faceted issues. Our understanding of them must be complex and multifaceted as well’ (p279).<sup>12</sup>

When vaccine hesitancy leads to *underimmunisation*, which we define as delaying or omitting some or all officially recommended vaccines, this provides an example of the underuse of a medical intervention considered to be safe and effective. Underimmunisation is a public health concern because it can reduce population protection, also referred to as *herd immunity*, towards certain potentially dangerous infectious agents and increases the risk of disease outbreaks.

Studies suggest that personal, social<sup>12-13</sup> and local cultural<sup>6</sup> networks are important determinants of vaccination decisions, in particular among those who under-vaccinate. Furthermore, people’s sources of information on health and vaccination-related information can play important roles in vaccination choices, with recent research pointing to the importance of ‘information overload’, ‘misinformation’ and higher levels of indecision among parents, particularly given the wide availability of (mis)information on the internet.<sup>14-18</sup>

Additionally, parent and provider perspectives that differ from official public health recommendations need to be considered in order to understand vaccine hesitancy.<sup>12</sup> These may include intuitive rather than analytical cognitive styles, reluctance to consider the evidence suggesting vaccine safety/efficacy, and lowered willingness to trust information delivered by public health authorities, as shown in an adherence to complementary and alternative medicine (CAM)-oriented health values and preference of CAM over biomedicine.<sup>19</sup> Studies also suggest that underimmunisation and usage of CAM are determined by similar factors, such as alternative concepts of body, immunity, risk perception, antiauthoritarian orientation, and distrust of biomedical establishment and the pharmaceutical industry.<sup>6,19</sup> Some of these associations may in part be due to confounding factors, such as higher income and education and distrust of medical systems.<sup>20</sup> Other sociomedical trends may also play a role in heightened patient participation in decision-making, such as

postmodern medicine,<sup>21</sup> characterised by risk culture,<sup>22</sup> healthism<sup>23</sup> and patients activating more agency in healthcare decisions.<sup>24</sup> Finally, research findings suggest limitations to the efficacy of the evidence-based strategies that have generally been employed by health authorities over the past decades to increase vaccination rates.<sup>19</sup>

A key determinant of patient vaccination decision-making seems to be the attitudes, behaviour and knowledge of their medical provider.<sup>25-27</sup> Important factors include the amount of time providers spend discussing vaccinations, their communication styles and the information available to providers.<sup>28-31</sup> As an example of medical providers’ influence on vaccination decisions, one study in the USA found that primary care providers with many parents who had vaccine exemptions for their children were more likely to have concerns about vaccine safety and were less likely to perceive individual and community benefits of vaccinations than primary care providers treating fewer children with vaccine exemptions.<sup>25</sup> A qualitative study into vaccination decision-making in the USA highlighted the importance of trust between healthcare professionals and parents.<sup>32</sup> Finally, the way that providers broach vaccination during consultations can have a determinative role in vaccination uptake, with one study recommending further investigation of participatory (ie, ‘What do you think about doing shots today?’) versus presumptive (ie, ‘Today, we are going to do some shots’) approaches during patient-provider interactions.<sup>26</sup>

### The Swiss context

In Switzerland, childhood vaccinations are usually given by private practitioners, predominantly paediatricians and general internists. There is no national mandate for vaccination in non-epidemic settings in Switzerland and no national vaccination registry. Despite this, vaccination coverage in Switzerland is high overall.<sup>33</sup> The FOPH makes vaccination recommendations and distinguishes between basic and complementary vaccinations. (*Basic* vaccines are defined as ‘essential to individual and public health, and offer a level of protection that is indispensable to people’s well-being (eg, diphtheria, tetanus, pertussis, polio, MMR (mumps, measles, rubella), HBV (hepatitis B), HPV (human papillomavirus)’ (pA51). *Complementary vaccines* are defined as being able to ‘maximize individual protection and are meant for individuals seeking protection from well-defined risks (eg, conjugate pneumococcal vaccine and conjugate meningococcus C vaccine)’ (pA51).<sup>34</sup> Both basic and complementary vaccines are reimbursed by basic mandatory health insurance when the official vaccination schedule is respected.

Given the absence of a national vaccination registry, the FOPH measures Swiss vaccination coverage at regular intervals.<sup>35</sup> Vaccination programmes and their implementation vary between the 26 cantons.<sup>34</sup> For example, children from the French-speaking and Italian-speaking cantons have on average higher rates of measles vaccination coverage than in German-speaking cantons.<sup>36</sup>



Cantonal coverage levels for HPV vaccination range from 79% (Valais) to 19% (Appenzell Innerrhoden) for two doses of HPV vaccine. HPV coverage estimates only include 16-year-old girls and estimates for boys are not yet available.<sup>37</sup> The most common reasons for women not being vaccinated against HPV, according to a 2014 survey, included being too old, lack of information, fear of side effects, being against vaccination in general or against HPV vaccination only, HPV vaccination felt to be unnecessary, and simple logistical issues,<sup>38</sup> with 7% and 6% of women not vaccinated against HPV reporting that the physician or friends/family recommended against HPV vaccine, respectively. Further research has shown that living in cantons with school-based vaccination increases uptake of HPV vaccination.<sup>39, 40</sup> However, spatial variation modelling has shown that variables such as political opinion, religion and community opinion might be additional determinative factors in the presence of school-based vaccination programmes.<sup>40</sup> This suggests further research is needed to better understand vaccine hesitancy and school-based vaccination programmes in Switzerland.

Vaccine hesitancy and underimmunisation seem to be specific to certain population subgroups.<sup>34, 41, 42</sup> For example, in Switzerland, measles cases, small epidemics<sup>43</sup> and underimmunisation cluster around children attending anthroposophic (ie, Rudolf Steiner, Waldorf) schools and around certain providers of CAM.<sup>41</sup> One cross-sectional survey (n=1007) was administered for paediatric patients in an urban paediatric emergency department in German-speaking Switzerland. Researchers found that those who did not fully accept basic vaccinations were more frequently CAM users than non-users, which researchers point to as reflecting parent wishes rather than physicians' recommendations.<sup>44</sup> This relationship merits further investigation and discussion.

Studies in Switzerland show high rates of CAM use and favourable opinions, with 25% of Swiss survey respondents aged 15 and older of the 2007 Swiss Health Survey stating that they had used CAM in the previous year.<sup>45, 46</sup> Other researchers assessed surveys conducted among the general population, doctors, hospitalised patients and obstetric institutions and found that approximately 50% of the Swiss population had used CAM and that 85% of the population would like the cost of CAM to be covered by basic health insurance.<sup>47</sup> CAM providers in Switzerland are often physicians trained in conventional medicine who have then obtained additional CAM training,<sup>48</sup> and basic mandatory health insurance reimburses four CAM services when provided by licensed physicians: (1) anthroposophic medicine, (2) traditional Chinese medicine and acupuncture, (3) homeopathy, and (4) phytotherapy.<sup>49</sup>

### Rationale for the research project

The scientific literature points to existing research gaps, such as a lack of detailed information on vaccine hesitancy, patient-provider communication in Switzerland, vaccination information sources and relations to the high prevalence of CAM use in Switzerland. This highlights the

interest in an exploratory mixed-method methods study investigating the vaccination perspectives and practices of patients and both CAM and biomedical providers. Our research focuses specifically on childhood vaccinations recommended in Switzerland<sup>50</sup> and on the vaccination against HPV, which is included in the Swiss FOPH recommendations for all adolescents 11–14 years of age. However, vaccination against HPV is recommended as a routine vaccination for females and as a complementary vaccination for males.<sup>50</sup>

### Objectives and aims

- ▶ To explore vaccine hesitancy and provide a detailed characterisation of its health system, patient-provider interaction, health communication, information sources, decision-making process, and demographic, geographical and sociocultural correlates in Switzerland.
- ▶ To assess the sociocultural and health system determinants of vaccine hesitancy and underimmunisation with childhood and HPV vaccines in Switzerland. This objective additionally aims at establishing the mediating effects of vaccine hesitancy on underimmunisation.
- ▶ To use the knowledge gained as the necessary background to design and submit a pilot intervention and to design tailored interventions to address vaccine hesitancy in Switzerland.

### METHODS AND DESIGN

Our research takes place in the setting of an ongoing Swiss national research programme (National Research Programme 74). The study protocol underwent successful peer review. For further information, refer to <http://www.nfp74.ch/en/projects/out-patient-care/project-tarr>. It represents a transdisciplinary<sup>51</sup> collaboration that views vaccine hesitancy as a complex, multifaceted phenomenon. Rosenfield<sup>51</sup> explains how *transdisciplinary research* can be conducted, particularly in health research: 'Representatives of different disciplines are encouraged to transcend their separate conceptual, theoretical, and methodological orientations in order to develop a shared approach to the research, building on a common conceptual framework. Such a framework can be used to define and analyze the research problem and develop new approaches for health care that more closely represent the historical and present-day reality in which health problems are situated' (p1351). The study team is composed of researchers and medical practitioners with a varied range of backgrounds and training. An infectious disease specialist and internist leads the core study team, which includes sociologists, anthropologists, and public health specialists who collaborate closely with a steering committee composed of clinicians trained in biomedicine and CAM, a researcher in anthroposophic medicine, public health experts and policy makers.

The project applies mixed methods through the use of a *sequential exploratory design* in order to study vaccine



Qualitative Data Collection	
August 2017 – March 2020	
<b>Childhood vaccines</b> August 2017 – December 2018 <ul style="list-style-type: none"> <li>- Semi-structured interviews               <ul style="list-style-type: none"> <li>• parents (N=40)</li> <li>• providers (N=15 CAM, N=15 biomedical)</li> </ul> </li> <li>- Ethnographic observations of medical consultations (N=15 CAM, N=15 biomedical)</li> <li>- Thematic and critical discourse analysis of vaccination information sources mentioned during interviews and observations</li> </ul>	<b>HPV vaccine</b> March 2019 – March 2020 <ul style="list-style-type: none"> <li>- Semi-structured interviews               <ul style="list-style-type: none"> <li>• parents (N=15)</li> <li>• school physicians (N=5)</li> <li>• youth (N=25 males, N=15 females)</li> <li>• public health officials (N=10)</li> </ul> </li> <li>- Family focus group discussions (N=15)</li> <li>- Ethnographic observations of school vaccination information sessions (N=10)</li> <li>- Thematic and critical discourse analysis of vaccination information sources mentioned during interviews and observations</li> </ul>
Quantitative Data Collection	
April 2018 – March 2020	
<b>Questionnaires</b> <ul style="list-style-type: none"> <li>- Childhood vaccine questionnaire               <ul style="list-style-type: none"> <li>• Parents of children 0 to 11 years of age (N=1,350)</li> </ul> </li> <li>- HPV vaccine questionnaires               <ul style="list-style-type: none"> <li>• youth 15-26 years of age (N=722)</li> <li>• parents of youth</li> </ul> </li> <li>- Provider questionnaire               <ul style="list-style-type: none"> <li>• providers (N≈150)</li> </ul> </li> </ul>	

**Figure 1** Study overview. CAM, complementary and alternative medicine; HPV, human papillomavirus.

hesitancy across Switzerland, meaning that we first begin with qualitative methods in order to inform the tools used for the data collection through quantitative methods.<sup>52</sup> An overview of the study design is shown in [figure 1](#). We recruit participants from the three major language regions of Switzerland (German-speaking, French-speaking and Italian-speaking) in order to examine vaccination decision-making throughout the country.

The qualitative and quantitative phases of the project both involve recruitment in medical providers' offices and interviewers with medical providers. For this purpose, we established a network of participating providers via the FOPH's Swiss Sentinel Surveillance Network and through direct recruitment by our research team. Our research team and advisory board include both CAM and biomedical providers, who have helped recruit their colleagues for this project, sharing recruitment documents (ie, invitation letters and study flyers), making telephone calls and employing snowball sampling. Ongoing provider recruitment efforts have enabled us to develop a network of over 150 CAM and biomedical providers from 21 of the 26 cantons and all three language regions in Switzerland.

For the study's qualitative component, we conduct semistructured, indepth interviews with parents, youth,

and biomedical physicians and CAM providers. We also observe vaccination consultations with parents and providers and HPV information events in schools. For the study's quantitative component, we recruit participants from the practices of the network of CAM and biomedical providers across Switzerland and perform quantitative telephone interviews with parents of children 0–11 years of age and youth aged 15–26 years. We also interview the participating providers. The collection of information about vaccine hesitancy from providers and their patients allows for a comparison of their perceptions of vaccinations.

Some providers participate in both the qualitative and quantitative research components, while most participate only in the quantitative phase. Importantly, our team had already established trusting relationships with a number of CAM physicians by the time of grant submission. These contacts have been crucial in expanding our network of CAM providers in Switzerland for the quantitative study phase.

### Qualitative methods

The qualitative methods of this research allow us to gain deeper insight into parent and youth vaccination decision-making and patient–provider interactions about vaccination in general practice settings. The qualitative methods additionally further our understanding about public health gaps in vaccination implementation programmes in Switzerland by paying attention to how participants discuss the Swiss health system in relation to vaccination. Finally, the qualitative methods inform the design of the quantitative study component tools.

The transdisciplinary research team drafted interview guides and medical consultation observation guides to be used as qualitative study tools. The interview guides were written based on relevant vaccine hesitancy literature and guide researchers through semistructured interviews with participants through the use of open-ended questions. Semistructured interviews involve researchers asking the same questions systematically to all participants, but allow the option for researchers to probe further by asking additional questions about themes emerging during the interview. The medical consultation observation guides allow researchers to systematically focus on items of interest highlighted in vaccine hesitancy literature on patient–provider interactions.<sup>28–31</sup> Both the interview guides and the observation guides were piloted for coherence and clarity.

An important concept in qualitative research to determine sample sizes is the concept of saturation, which indicates that similar results are consistently collected during data collection and adequately address the research questions at hand. When saturation has been attained in qualitative research, researchers can reasonably expect similar results if the research process were to continue.<sup>53 54</sup> We expect to reach data saturation with the number of qualitative face-to-face interviews and observations mentioned



below, but the qualitative nature of this approach allows us flexibility in adjusting the amount of data to be collected.

#### Qualitative interviews with biomedical and CAM providers

We conduct indepth, semistructured qualitative interviews with at least 15 CAM providers and at least 15 biomedical physicians in providers' offices. Interview questions are organised by theme, including (1) contextual information about the providers (ie, type of training, type of medicine practised, years of clinical experience and descriptions of the types of patients they treat); (2) questions about interactions with their patients and typical vaccination consultations (ie, amount of time spent discussing vaccination, communication strategies and perceptions about communication training); and (3) views and perspectives on medicine, immunity and the body (ie, information sources on vaccinations, perceptions about their advantages and disadvantages, 'natural acquired immunity' vs vaccine-acquired immunity, public health benefits compared with individual choice considerations, and vaccination rates and public health approaches in Switzerland). The interviews are audio-recorded and transcribed verbatim. If participants request transcriptions, we provide them so that they may clarify anything that they discussed.

#### Ethnographic observations of vaccination consultations

We observe a total of 30 vaccination consultations (15 with CAM providers, 15 with biomedical providers) with 10 different providers (5 CAM, 5 biomedical). We ask willing providers to allow us to observe consultations during which they discuss vaccination with parents for the first time. Prior to consultation observations, researchers discuss how they are conducted, with both providers and patients having the option to not be observed. In cases of reluctance to participate, potential participants are able to ask questions about the study, and researchers provide them with written information about the study. We do not observe participants who do not wish to participate in the study. To date, providers not wishing to be observed are uncommon, and no patients have refused being observed. Providers explained these rare refusals by describing how they did not wish researchers' observations to disturb the natural flow of consultations with patients, not having enough time or not seeing enough patients with whom they discuss vaccination for the first time on a daily basis.

Researchers take ethnographic field notes about the observation in field journals in order to document what happens during the interactions. They then fill out a medical consultation observation guide, which prompts them to record information about patients and providers, the reason for the consultation, who initiated the vaccination discussion, if vaccinations were discussed in a participatory or presumptive manner, questions asked by patients, if and how patients expressed hesitancy towards vaccination, researchers' perceptions of the patients' ability to understand the vaccination discussion, the vaccination decision, the amount of time spent

discussing vaccination, information source materials, and the researchers' perceptions of the mood, emotions and communication between parents and providers. After observing the medical consultations, researchers use ethnographic field notes and the observation guide as the basis to write observations into a descriptive narrative format of each observed consultation.

#### Qualitative interviews with parents

We conduct indepth qualitative interviews with 30 vaccine-hesitant parents and 10 parents who vaccinate according to the FOPH vaccination schedule. Interviews are conducted in their homes or in a place of their choosing, such as a coffee shop. We purposefully sample more vaccine-hesitant parents, particularly those who consult CAM providers for their children, since an important study assumption is that vaccine hesitancy, underimmunisation by parents and their usage of CAM are codetermined. We ask parents questions thematically about (1) family composition and parental roles (ie, work, childcare, child healthcare decisions); (2) children's health, healthcare and lifestyle (ie, types of healthcare professionals parents consult for their children, health beliefs and practices, CAM use, preventive practices, and so on); (3) immunisation status of the children with the support of vaccination booklets during the interview; (4) vaccination perspectives (views on individualised vaccination calendars and views on the public health benefits or consequences of vaccination); and (5) vaccination experiences (the vaccination decision-making process, vaccination discussions with healthcare professionals and others, and perceptions of social pressure to vaccinate or not vaccinate).

#### Qualitative research focus on HPV vaccination: youth and parents

There are limited published data on adolescent female views on HPV vaccine<sup>38 55</sup> and no data on adolescent male views on HPV vaccine in Switzerland. Therefore, we also conduct qualitative indepth interviews with approximately 40 youth (approximately 25 males and 15 females) recruited through the HPV quantitative research discussed below. Interviews take place in participants' homes or in a place of their choosing, such as a coffee shop. We purposively sample more male youth since there is no literature on male perspectives on HPV in Switzerland, and HPV vaccination recommendations are more recent for males than females. If youth provide their consent, the parents of 15 youth are interviewed separately and in family focus group discussions (FGD) together with the youth. Themes of the interviews and FGD include (1) questions relating to family composition and parental roles; (2) youth health, healthcare and lifestyle (ie, types of healthcare, professionals young adults/adolescents consult, health beliefs and practices, CAM use, preventive practices, and so on); (3) HPV immunisation status; (4) HPV perspectives; and (5) HPV vaccination experiences and the vaccination decision-making process. This last theme focuses particularly on discussions with parents, friends,



acquaintances, significant others, potential sexual partners, information sources, schools' roles in providing vaccination information, and how or if the youth ever felt any social pressure to vaccinate or not vaccinate against HPV.

#### Qualitative research focus on HPV vaccination: schools and public health officials

We observe 10 school information activities about HPV vaccines in three to four cantons. We choose cantons based on convenience in terms of access and ethical clearance to conduct ethnographic observations for research purposes. Researchers attend school-based events during which the HPV vaccination is presented to youth. In classrooms, our researchers explain to students and instructors that we are there to observe and take notes on the content of the discussions as part of a study that examines how this type of information is communicated in schools. No identifying information is documented or included in any dissemination of research results. Observation notes are documented in field journals and subsequently written into a descriptive narrative format.

We purposively sample an estimated two to three public health officials from the FOPH, two to three cantonal authorities, and approximately five school physicians for expert interviews (n=10–15) in order to gain further information about how recommendations are made, discussed, planned and implemented from a public health perspective. Interviews focus on perceptions of the implementation of vaccination programmes from public health authority perspectives and are informed by specific questions from our qualitative enquiries.

#### Vaccination information sources

In order to better understand how information sources affect parent, youth and provider decision-making processes, we document and analyse sources of information that they discuss during the qualitative and quantitative interviews and medical consultation observations using both thematic analysis<sup>56</sup> and critical discourse analysis.<sup>57–59</sup> Since the internet's role in vaccine-related decision-making is well documented in the literature,<sup>14 15 60–62</sup> we are particularly interested in parents' and youth's use of and interactions with internet sources.

#### Qualitative data analysis

The following are the primary research questions guiding the conduct of the qualitative research: (1) How do parents and youth make vaccination decisions? (2) How do medical providers, both CAM and biomedical, consider what vaccination recommendations to make to their patients? (3) How do medical providers discuss vaccination with parents and youth? (4) How are vaccination implementation programmes envisaged from a public health perspective?

We use the Consolidated criteria for Reporting Qualitative research checklist<sup>63</sup> as guidelines for reporting items of interest in the presentation of qualitative results.

Since we work with diverse sources of qualitative data, we use the framework method<sup>64</sup> and grounded theory, particularly *constructivist grounded theory* as outlined by Charmaz,<sup>65</sup> as guiding principles for our analysis. This allows our research team to structure an analytical framework throughout qualitative data analysis with the use of *sensitising concepts* and to code data into relevant research themes while still being open to including categories and themes that emerge through qualitative data collection and analysis. Data are coded primarily by the interviewers, with coded segments being discussed with various members of the research team.

Sensitising concepts are used in qualitative research in order to guide researchers to selectively focus on emerging themes and categories relevant to the research questions<sup>66</sup>; for this research, sensitising concepts include patient–provider interactions, provider and patient interaction with information sources, health beliefs and practices, and interactions with and perceptions of the Swiss health system.

With the focus on patient–provider interactions in vaccination decision-making, the choice to research these questions by interviewing parents, youth and medical providers and observing vaccination consultations allows us to triangulate our qualitative data in order to account for the 'multiple realities' of medical consultations.<sup>67</sup> Finally, in order to fully appreciate the complexity of how people interact with health information in order to make vaccination choices, we will conduct both thematic analysis<sup>56</sup> and critical discourse analysis<sup>57–59</sup> of any sources of information mentioned as being important or determinative during vaccination discussions. A first manuscript containing initial results of the qualitative research phase has been published.<sup>68</sup>

#### Quantitative methods

The quantitative phase of our study seeks to explore and quantify the determinants of vaccine hesitancy and underimmunisation with childhood and HPV vaccines in Switzerland. To this end, we developed questionnaires targeted at the different populations included in our study.

#### The questionnaires

As childhood and HPV vaccinations involve different populations and are generally viewed differently by patients, we survey two separate populations: parents of young children and youth (and their parents, if possible). In addition, we survey providers to gain a better understanding of views on vaccination in our diverse network of participating providers and the relationship between provider and patient views on vaccination.

To fully explore vaccine hesitancy and underimmunisation in these diverse populations, we developed four separate questionnaires: (1) a childhood vaccination questionnaire to be administered to parents of young children; (2) an HPV vaccination survey for youth; (3) an HPV vaccination survey for parents; and (4) a questionnaire



for providers. As Switzerland is a multilingual country, we developed versions of the questionnaire in the three main national languages, German, French and Italian. In addition, given the large number of immigrants living in Switzerland, we developed an English version of the questionnaire for those who preferred doing the interview in English.

Parent and youth surveys include questions about basic sociodemographic factors, including household composition, work and educational background, income, migration status and language knowledge. In order to maximise comparability with other surveys and to allow us to weight samples so that results are more representative, we drew these questions from two recent representative national surveys in Switzerland: the Swiss version of the European Social Survey 2014 (ESS 2014)<sup>69</sup> and the 2012 Enquête Suisse de la Santé.<sup>70</sup>

As vaccine hesitancy is often correlated with political beliefs<sup>71</sup> and religious beliefs,<sup>72</sup> we also include a series of questions on political and religious beliefs and practices drawn from the ESS 2014. We include three questions on each theme. For religion, we ask about interviewees' religious affiliation, the frequency with which they attend religious services and their perceptions of their own religiosity. For political beliefs, we ask about interviewees' level of interest in politics, which political party they feel close to and where they place themselves of a left-right political scale.

In addition, all questionnaires include the 20-item Moral Foundations Questionnaire<sup>73</sup> based on the finding in a recent US study<sup>74</sup> showing that moral foundations are associated with vaccine hesitancy. These survey items were all already extensively published and available in our survey languages and did not require translation or validation.

We measure underimmunisation through examination of participants' vaccination records. We measure vaccine hesitancy using the 15-item Parent Attitudes about Childhood Vaccines (PACV) survey instrument, a validated measure of vaccine hesitancy and underimmunisation.<sup>75</sup> We use the original survey instrument for the childhood vaccination questionnaire and adapted questions to be appropriate to the target population for the parent and youth versions of the HPV questionnaire. For the provider questionnaire, we adapted the version of this instrument to measure vaccine hesitancy among childcare facility directors.<sup>76</sup>

Based on preliminary findings in the qualitative phase, we developed new questions around several themes, including (1) communication about vaccination with medical providers; (2) information sources consulted in vaccination decision-making; (3) perceptions about risk and control concerning possible exposure to vaccine-preventable diseases; and (4) the parent-provider relationship. For the HPV vaccination surveys, we also developed questions specific to this vaccine and its administration in Switzerland, including questions on knowledge of HPV vaccine, sources of HPV vaccination and

perceptions of school-based vaccination programmes. In addition, we ask both parents and youth a series of questions about health, including questions about health status, CAM usage and medical care usage. The provider questionnaire also asks for details about providers' practices, particularly with regard to their practice of CAM. The questions we developed that are based on preliminary findings from the qualitative phase are listed in online supplementary appendix 1.

French, German and Italian versions of the PACV15 were not available, so these questions and the new questions developed for these questionnaires were translated into French, German and Italian. Thirty-three key questions including the PACV and questions developed based on preliminary results of the qualitative portion of the study were translated using the forward and backward method. Two independent translators first translated into the target language (German, French or Italian) and then reconciled any disparities in their translations. Next, two different, independent translators who were blinded to the original questions translated them back into English.

Once developed, we pretested and piloted the childhood vaccination and HPV versions of our questionnaires in all languages. For the pretest, we recruited a convenience sample of 61 individuals to test the questionnaires in all four survey languages. We pretested each version of the questionnaire with two to seven people and adjusted based on feedback. We then piloted the adjusted questionnaires using our full recruitment procedure (see 'Recruitment and survey populations'), conducting a further 56 interviews with the three questionnaires in the four survey languages. Finally, we pretested the provider questionnaire among providers in German, French and Italian. The questionnaire was also shared with the project's advisory board and adjusted based on their feedback.

#### Power analyses

##### *Childhood vaccination survey*

A conservative estimate is a proportion of 15% vaccine-hesitant parents in the practices of the participating biomedical and CAM providers combined (NB: 7% unvaccinated and 12% children with delayed vaccination were recorded in the 2012 FOPH survey).<sup>77</sup> The sample size calculation aims at identifying the number of participants needed to detect a significant association of specific individual risk factors with vaccine hesitancy, which is here considered as a binary outcome. We further assume that factors potentially associated with vaccine hesitancy are prevalent in 20% of the population and that the OR between vaccine hesitancy and a relevant risk factor is at least 2. In this case, to detect a statistically significant association with such a risk factor at the level of 0.05 with a power of 0.8, 675 participants are needed. Due to the recruitment in selected provider practices, a certain clustering of parents' characteristics is to be expected for parents recruited in the same practice, in contrast to a simple random sample. To account for such clustering, a design effect of 2 is conservatively assumed, leading to

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a total sample of 1350 parents to be interviewed. This would equally allow detecting a 10% lower proportion of vaccination among parents who are vaccine-hesitant compared with a vaccination rate of 90% in the remaining population.

#### HPV vaccination survey

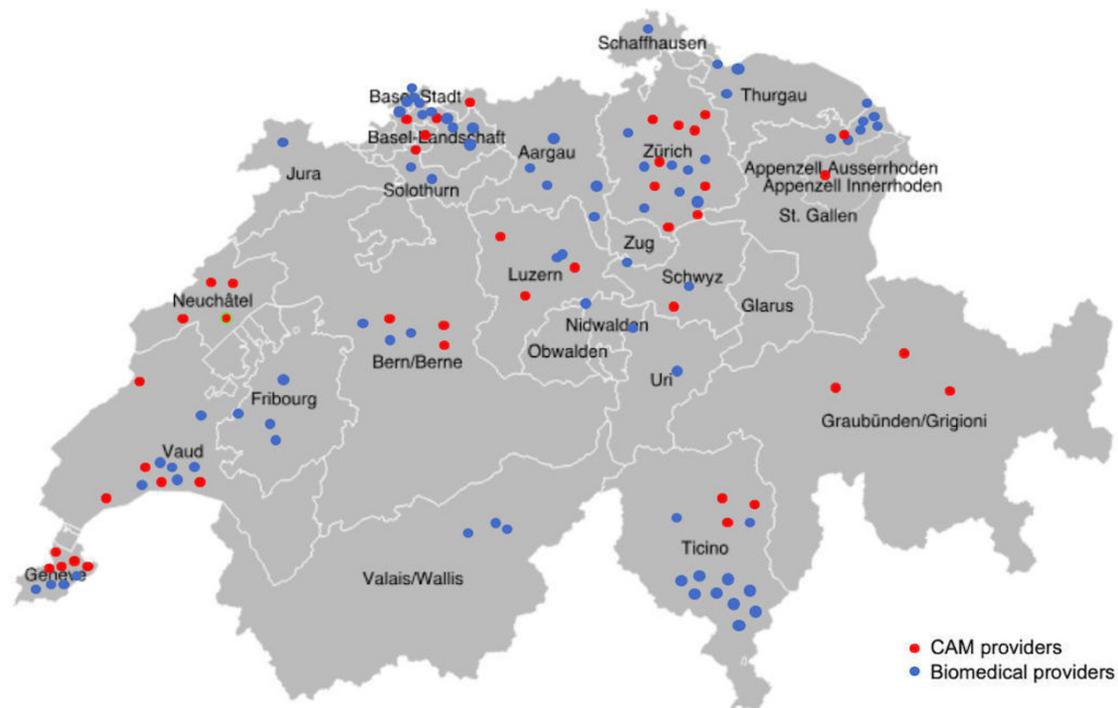
To investigate vaccine hesitancy and associations with underimmunisation in the case of HPV vaccination, a separate sample of participants is required. Similar to the first case, we might also assume 15% vaccine-hesitant participants, and we further anticipate a 30% lower rate of vaccination among vaccine-hesitant persons than in the entire population. With a given prevalence of HPV vaccination of 53%, this would mean that among vaccine-hesitant persons only 37% would be vaccinated. With power=0.8 and alpha=0.05, a sample of 593 participants would be needed. To account for clustering, assuming a design effect of 2, the final sample would include 1186 participants. However, more likely is a higher vaccine hesitancy rate of 30%, given the relative novelty of HPV vaccines and the fact that it has been recommended in boys/adolescents only for the past 3 years. With power=0.8 and alpha=0.05, a sample of 361 participants would be needed. To account for the cluster sample, assuming a design effect of 2, the final sample would include 722 participants.

Based on the above power analyses, our study populations include 1350 parents of children aged 0–11 for the childhood vaccination study and 722 young people aged 15–21 years (for young women) or 15–26 years (for young men) for the HPV vaccination study.

As mentioned, there is regional and linguistic variation regarding *vaccination uptake* in Switzerland in the setting of different cantonal levels of school vaccination programmes<sup>39 78</sup> and health authority support for vaccination programmes.<sup>79</sup> On the other hand, we expect the prevalence of *vaccine hesitancy* and of its determinants to be relatively homogeneous across different geographical and language regions of Switzerland. Therefore, we do not specifically take geographical and language heterogeneity into account for the outcome *vaccine hesitancy*. Moreover, conditional on this assumption being correct, the statistical power to detect an association between vaccine hesitancy and the likelihood of obtaining HPV vaccination would not be sizably smaller in the presence of geographical or language heterogeneity in HPV vaccination rates than without such heterogeneity.

#### Recruitment and survey populations

We recruit our participants through the offices of the network of CAM and biomedical providers. As [figure 2](#) shows, our provider network includes more than 150 CAM and biomedical providers working in all three language



**Figure 2** Network of participating providers. CAM, complementary and alternative medicine.



regions in Switzerland and in almost every canton. Each dot represents a practice participating in the study: red dots represent CAM practitioners and blue dots biomedical providers. To ensure confidentiality, we place dots in the correct canton but do not place them at the exact provider location. Group practices are represented by a single dot.

Providers are CAM or biomedical providers who treat children and/or youth and regularly deal with questions regarding vaccinations and vaccine decisions. They include paediatricians, general practitioners, gynaecologists, CAM physicians and CAM providers without formal medical training working independently or in group practices.

We interview parents and young people by telephone. Each telephone interview lasts approximately 30–35 min. Parents are recruited from urban and rural medical practices in French-speaking, German-speaking and Italian-speaking areas of Switzerland. In addition, we interview each participating provider in order to examine the relationships between provider perspectives, patient perspectives and vaccine hesitancy. For the HPV portion of our study, we interview one of the participating youth's parents if the youth allow us to do so.

To be eligible to participate in the study, participants fulfil the following criteria. For the childhood vaccination substudy, parents are 18 years old or older with a child aged 0–11. For the quantitative HPV portion of our study, young women are between the ages of 15 and 21 (born between 1 July 1997 and 1 July 2003) and young men are between the ages of 15 and 26 (born between 1 July 1992 and 1 July 2003). These differences are due to the timing of HPV vaccine recommendations for girls and boys. HPV vaccine reimbursement for girls 11–14 (target age) and 15–19 (catch-up age) started 1 January 2008. HPV vaccination reimbursement for males began on 1 July 2016 in Switzerland. Given the newness of this recommendation, we enrol youth males born between 1 July 1992 and 1 July 2003 in order to gather data on all males aged 15–26 who have been eligible for the HPV vaccine through Swiss vaccine programmes. All study participants (parents, youth and providers) must speak one of the main Swiss national languages (French, German or Italian) or English.

We recruit all parents and youth through providers in order to be able to link the data from the parents with their provider's data for a comparison by type of provider. We use a quota sampling technique as CAM providers are likely to see fewer patients per day. Our goal is to recruit a maximum of 20 parents of young children and a maximum of 15 youth per provider based on a rigorous sampling approach in a defined period. Recruitment targets for group practices are no more than three times the target for individual providers. Thus, targets in dual practices are 40 parents and 30 youth, and for practices with three or more providers, targets are 60 parents and 45 youth. For every practice, the total number of eligible patients in a specific time period will be established,

which allows post-hoc weighting to the known total of eligible patients in this time period.

Given the diversity of providers and differences in our study subpopulations, we employ a variety of recruitment techniques. In large practices or practices with high patient volume, interviewers recruit participants directly in providers' waiting rooms. Interviewers are medical students trained in recruiting participants, obtaining informed consent, conducting quantitative interviews over the telephone and quantitative data management. For inoffice recruitment, interviewers spend 2–5 days in providers' waiting rooms, with the goal of recruiting a maximum of 20 parents and/or a maximum of 15 youth for interviews. Interviewers contact all eligible patients to present the study and ask whether they are interested in participating. For those who agree, interviewers obtain informed consent and a copy of the vaccination certificate (if possible) in waiting rooms and then arrange to conduct a telephone interview at a later time. In large group practices, interviewers have the option to work as a team to manage particularly high patient volumes.

In smaller practices or practices with lower patient volumes for the targeted groups, we ask providers to recruit participants retrospectively by reviewing their patient log from the last 2–6 months and contacting eligible patients to see if they would be interested in participating in the study. Providers transmit a detailed record of attempted contacts and take note of refusals and interested parties. We then contact those who indicate an interest by phone to present the study, obtain informed consent and a copy of the vaccination certificate (if possible), and arrange for a telephone interview. Interviewers select potential participants randomly from the lists provided until they have the required quota of participants in each group.

Interviewers determine the most appropriate recruitment technique during a first visit with the provider. As some providers may have high volumes of one population and low volumes of another (eg, paediatricians may see many young children but few youths 15 of age or over), we may employ different recruitment methods for the different subsamples.

Experience to date shows that providers generally accept our preferred recruitment practice for their type of practice. However, we work with providers to find workable solutions if they are uncomfortable with or unable to accommodate our standard recruitment procedures. Although small practices, particularly for CAM providers, are often hesitant to let interviewers recruit in waiting rooms, such practices rarely have sufficient patient volume to merit that approach. Very few large-volume providers have been unwilling to allow interviewers to recruit in waiting rooms; however, when they are, we implement the provider recruitment practice used in smaller practices. More commonly, practices do not have the capacity to review patient logs and contact patients. In that case, as approved by the local ethics commissions, interviewers can assist medical providers and their



assistance in reviewing logs and contacting patients from providers' offices.

For all recruitment techniques, we track how many people were contacted, how many agreed to participate or be contacted again, how many gave consent to interviews, and how many completed interviews. This information will allow us to assess the refusal rate, the dropout rate and the number of individuals lost to follow up.

Additionally, we conduct a quantitative telephone or face-to-face survey with all participating providers during the quantitative component of the study in order to quantitatively assess if providers' vaccine perspectives are associated with those of their patients.

#### Quantitative data analysis

The following are our primary quantitative research questions:

- ▶ What are the determinants of vaccine hesitancy for childhood and HPV vaccinations in Switzerland?
- ▶ What is the relationship between vaccine hesitancy and underimmunisation?

We measure vaccine hesitancy based on the PACV score. As this instrument has not previously been used in Switzerland or in our survey languages, we first test its validity for Switzerland using Mokken Scale analysis to confirm the unidimensionality of the scale. Individuals with a PACV score of  $\geq 50$  are considered vaccine-hesitant, and individuals with a PACV score  $< 50$  are not considered vaccine-hesitant.<sup>75</sup> We will use multilevel logistic regression to assess the influence of different variables on vaccine hesitancy. We will explore associations between vaccine hesitancy and a number of individual-level characteristics, including age, sex, household composition, place of birth, immigration status, household income, employment status and work hours, daycare usage, highest achieved level of education, political affiliations, religion, CAM usage, trust in medical providers and satisfaction with consultations, sources of information about vaccination consulted, views on parents' role in vaccine decisions, views of importance of health, views of risks of vaccine-preventable diseases, and moral foundations. In addition, our research design allows us to explore how factors at higher levels are associated with vaccine hesitancy, including how vaccine hesitancy varies by canton and language region and by provider or by various provider characteristics (CAM vs biomedical providers), and to what extent vaccine hesitancy of the parent/youth correlates with vaccine hesitancy of the provider. Finally, although our data are not representative, we can weight results to allow us to roughly estimate the prevalence of vaccine hesitancy in Switzerland.

#### Study status

This study is ongoing, with some parts of the research completed, others ongoing and others yet to begin. For the qualitative portion of the study, we have completed qualitative interviews with biomedical and CAM providers and ethnographic observations of vaccination consultations.

We have also completed qualitative interviews with parents of young children. Qualitative interviews with youth and parents focusing on HPV vaccination are ongoing. We are at the recruitment stage for our qualitative research on HPV vaccination at schools and with public health officials. Finally, we are compiling a list of vaccination information sources based on responses to questions related to this subject in the quantitative questionnaires and discussions in qualitative interviews with parents and youth. We will begin analysis once this list is complete, at the end of data collection for qualitative interviews and the questionnaires. For the quantitative portion of our study, we have completed questionnaire design and testing and the power analysis to determine sample size. We are currently recruiting and interviewing parents, youth and providers for the survey, with approximately half of interviews completed. We continue to recruit providers as well.

#### DISCUSSION

By using a sequential exploratory mixed-methods study design,<sup>52</sup> this study will provide rich and multifaceted data on vaccination decision-making and vaccine hesitancy in Switzerland. In line with such a study design, the qualitative data informed the tools used for the quantitative data collection component. The results of both qualitative and quantitative components of our study will likely be complementary to one another and will allow us to answer different types of research questions. That said, any discrepancies or contradictory findings between the qualitative and quantitative components will merit further investigation, which we will highlight in the dissemination of study results. Additionally, given the multifaceted nature of vaccine hesitancy and health decision-making and the study's exploratory mixed-methods study design, the results from both qualitative and quantitative components will provide us with rich and detailed data for the Swiss context, where there is limited available data.

A particular strength of this study is its focus on perspectives of both medical providers and their patients. Studies have shown that providers remain a trusted source of information for parents and youth facing vaccine decisions, so a greater understanding of provider perspectives is important.<sup>25–32</sup> Another major strength of this study is its inclusion of the perspectives of both CAM and biomedical providers. While a growing literature explores the association between vaccine hesitancy and CAM usage,<sup>6 12 19 20</sup> few studies include the perspective of CAM providers and none that we know of has the extent of cooperation with CAM providers found here.

Qualitative interviews provide key insights into parents, youths, and CAM and biomedical providers' perspectives on vaccination. In addition, interviews with CAM and biomedical providers shed light onto their views on vaccination, vaccine-hesitant patients and how they interact with this population in their practices. Observations of vaccine consultations in offices provide another opportunity to get a sense of the variety of approaches providers



employ when broaching the subject of vaccination. The combination of qualitative interviews with numerous stakeholders in vaccine decision-making and planning, ethnographic observations of vaccination consultations and school information sessions about the HPV vaccination, and qualitative analysis of vaccination information sources allows for qualitative triangulation into the multifaceted phenomenon of vaccine hesitancy in Switzerland. Such a triangulation of qualitative data through multiple qualitative methods allows us to better understand the 'multiple realities' of medical consultations,<sup>67</sup> in addition to allowing us to explore how various actors interact with and perceive the Swiss health system in regard to vaccination.

Although data are not strictly representative of Switzerland, data from the quantitative survey gives us a sense of the overall prevalence of vaccine hesitancy in Switzerland and how this varies between language regions, cantons, and urban, suburban and rural settings. More importantly, it allows us to explore the association of vaccine hesitancy with other factors, like CAM usage, religion and spirituality, moral foundations, and political orientation. In addition, by pairing data from providers and their patients, we can see whether there is an association between providers' and patients' views on vaccines. The quantitative data also provides us with insight into the major sources of information parents and youth draw on when making vaccination decisions. Finally, the mixed-methods study design allowing for the qualitative component to inform the quantitative component also allows us to triangulate both the qualitative and quantitative data gathered throughout the duration of the study so that results from both components can be compared.

### Limitations

There are several limitations to the various parts of our study. A major limitation, which we also argue should be seen as a study strength, comes from our focus on recruiting participants through providers. This technique has major advantages when seeking to examine effects of provider characteristics on patient beliefs and behaviours, particularly for a topic such as vaccine hesitancy where trust between patients and providers has been shown to be a major determinant.<sup>32</sup> We also included items in both qualitative interview guides and quantitative questionnaires in order to gauge to what extent patients select physicians they trust or whose practices or attitudes align with their own, a patient practice which has been documented in vaccine hesitancy literature.<sup>80</sup> These questions also allow us to assess if disagreements between patients and providers have brought patients to seek care elsewhere in more provider-driven selection processes.

The quantitative component recruitment strategy indicates that populations that do not regularly see medical providers are under-represented in our data. While universal health insurance requirements attempt to ensure that most people living in Switzerland have access to healthcare, certain populations are still

under-represented, including recent migrants and undocumented populations. Recruiting through providers poses further questions of selection bias, as people who see doctors more often are more likely to participate in our study. This bias means that, for example, parents of infants were more apt to be recruited than parents of older children, as infants see the doctor more regularly. Selection bias problems are particularly relevant to youth populations, as most youth are healthy and thus among the least likely to regularly seek medical care. As such, youth in our study may differ in important ways from youth in Switzerland overall. In addition, as our provider network was established through personal recruitment by members of the study team and snowball sampling, the network itself is not representative and subject to selection bias. In our view, the advantages of being able to link provider and patient data outweighed these limitations.

For qualitative interviewing, interviewer effects may affect the type and quality of information we received; interviews and observations are conducted by a male medical sociologist trained in qualitative research methods, a female medical doctor trained in qualitative research methods, a female senior medical student with qualitative research training, and a female medical anthropologist trained in qualitative research methods. That being said, having a variety of researchers with different backgrounds involved in the data collection and analytical process adds to the richness of the analysis through clarification of concepts during indepth research team discussions. Another limitation arises from the way we observed vaccine discussions. Observers watch the discussion in person and take notes, but do not audio-record or video-record discussions. The absence of such recordings limits our ability to rigorously analyse the conversations, while the physical presence of observers in the consultation may have had an effect on discussions. Furthermore, given that the data are collected in both French-speaking and German-speaking regions of Switzerland, we have a multilingual corpus which necessitates indepth discussions between study members during qualitative data analysis.

Furthermore, as noted above, the quantitative study is not based on a representative sample but instead allows to compare results between different types of providers and their patients, and between different sociocultural regions of Switzerland. As in the qualitative component, interviewer effects may affect the type and quality of information we received. We will include data quality controls into data analysis in order to check for interviewer effects. Additionally, linguistic barriers, particularly with recent migrants to Switzerland, may prove challenging for participants to provide accurate responses to our interview questions.

### Scientific relevance

Vaccine hesitancy is a complex public health issue in high-income countries, yet there is no agreed-on measure of vaccine hesitancy. Multilingual, validated



instruments for measuring vaccine hesitancy are rare, making comparative study difficult. This study develops and test translations of the 15-item PACV in three new languages and provides valuable assessments of vaccine hesitancy in French-speaking, German-speaking and Italian-speaking contexts. Furthermore, our study design includes vaccination certificates in order to statistically examine the relationship between vaccine hesitancy and underimmunisation.

Results from the study make a contribution to the literature on the relationship between CAM usage and vaccine hesitancy. The combination of rich qualitative data including both biomedical and CAM perspectives and provider-linked data from patients who see CAM practitioners allows for a more in-depth examination of this relationship than found in the literature to date.

A combination of the data collected through the quantitative and qualitative methods and their analysis will form the necessary background for the design, submission and implementation of an appropriate randomised control trial intervention designed at improving vaccine communication and counselling among physicians, parents and adolescents in Switzerland.

#### Patient and public involvement

Study participants, both patients and medical providers, are involved in the study design throughout the duration of the data collection. Study tools are piloted and tested by the research team who requests patient and provider input during this process. Participants are given the opportunity to indicate any additional comments throughout data collection so that we may take their priorities, experiences and preferences into account. Patients (parents and adolescents) and providers assist us in additional recruitment efforts as described in the Methods and design section. All participants were informed of the amount of time their participation would entail prior to data collection. We systematically request participants' wishes to receive the results of the study by including an item on the consent form allowing them to provide us with their contact information. We will send relevant published results to study participants and invite them to public forums where we discuss our study results.

#### ETHICS AND DISSEMINATION

As approved by the ethics committee, all questionnaire items include 'do not wish to answer' categories, given the personal and sensitive nature of certain questions, in particular those regarding religion and political views. In accordance with the Human Research Act (HRA), adolescents (defined as individuals 14 years of age or older) who are capable of judgement are able to provide informed consent in writing and do not need to provide informed consent in writing from a legal representative 'if the research project entails more than minimal risks and burdens' (HRA, Art 23, Par 1). Ethikkommission Nordwest- und Zentralschweiz has approved of this study

as entailing less than minimal risks and burdens and thus does not require informed consent in writing from a legal representative for adolescents. Informed consent from minor participants (all aged 15 years and older for this study) is obtained directly from the participants and not their legal representatives.

Study results will be published in peer-reviewed academic journals and disseminated to healthcare professionals, researchers and the public via academic conferences and public presentations. The data sets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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#### Presented at

Some of the study's methods and preliminary findings have previously been presented at the following conferences: (1) Notter J, Deml M, Huber B, Krüerke D, Jafflin K, Zeller A, Mäusezahl M, Berger C, Merten S, Burton-Jeangros C, Pfeiffer C, Tarr PE. Poster presentation at SSI (Swiss Society for Infectious Diseases) Joint Annual Meeting in Interlaken, 14 September 2018: 'Complementary and alternative medical (CAM) providers' patient-centered, individualized approaches to vaccination in Switzerland'; (2) Tarr P. Oral presentation at Global challenges in vaccine acceptance science and programs, 24–26 September 2018 - Les Pensières Centre for Global Health, Veyrier-du-Lac, France: 'Approaches of complementary and biomedical providers to vaccinations in Switzerland'; (3) Deml M. Oral presentation at Swiss Public Health Conference in Neuchâtel, 8 November 2018: 'Vaccination Policy, Vaccine Uptake, and Vaccine Hesitancy in Switzerland'.

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**Contributors** MD codrafted the manuscript and focused on the qualitative components. KJ codrafted the manuscript and focused on the quantitative components. SM initiated the drafting of the manuscript and provided valuable feedback during its writing. BH assisted in establishing a network of complementary and alternative medical (CAM) practitioners and provided expertise in both paediatrics and CAM in the Swiss context. AB participated in developing the methods for the qualitative research specific to HPV. EF, VM, JS, PK and RC coordinated quantitative data collection efforts and were instrumental in the preparation of the study's quantitative tools and data management. DK participated regularly in study advisory board meetings and provided insight into CAM perspectives and feedback about the study design. CP took a lead role in establishing the study's qualitative methodologies. CB-J provided regular study supervision and inputs about the qualitative results. PT is the principal investigator, directed the funding request and supervised the conduct of the study in its entirety. He provided infectious disease and general medical expertise, and oversaw study conception, design, data collection, analysis and interpretation. All authors read, contributed to and approved the final manuscript.

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**Ethics approval** The study is conducted in compliance with the study protocol, the Swiss Federal Act on Research Involving Human Beings (Human Research Act) and the Declaration of Helsinki. The study was approved by the local ethics committee (Ethikkommission Nordwest- und Zentralschweiz, EKNZ; project ID number 2017–00725), and ethics approval covers all study participants, including adolescent and adult patients, as well as biomedical and CAM providers. All study participants receive information about the study and provide written informed consent.

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## Chapter 3

# “We treat humans, not herds!”: A qualitative study of complementary and alternative medicine (CAM) providers’ individualized approaches to vaccination in Switzerland

### Notes

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## "We treat humans, not herds!": A qualitative study of complementary and alternative medicine (CAM) providers' individualized approaches to vaccination in Switzerland



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### ABSTRACT

Complementary and alternative medicine (CAM) providers' roles in parents' decision-making about vaccinations for their children have only recently begun receiving research attention, despite studies showing CAM to be used by 25–50% of the population in Western countries. This article examines how CAM practitioners discuss vaccinations with parents in Switzerland, with a focus on childhood vaccinations and human papillomavirus (HPV) vaccinations. We describe how the CAM providers we interviewed (N = 17) and observed during vaccination consultations (N = 18 observations with 5 providers) employed individualized approaches to vaccination. Triangulation of qualitative evidence from interviews and observations allowed us to analyze their discourses and descriptions of experiences (i.e. what they said) and their practices *in situ* (i.e. what they did). Evidence gathered shows that practitioners framed vaccination decisions as choices at individual and family levels rather than focusing on public health benefits and consequences. They articulated their perspectives in terms of personal clinical experiences and parents' wishes, concerns, and contexts. Such findings challenge recurring narratives depicting CAM providers as categorically anti-vaccination and suggest that approaches to address vaccine hesitancy in clinical practice could benefit from communication and relational approaches similar to those demonstrated by participants in this study. Such approaches include taking time to understand parents' wishes, involving them in vaccination decisions, and taking their concerns seriously.

### 1. Introduction

The growing body of research on vaccine hesitancy (VH) underscores how drivers of vaccination decisions are multifaceted. Since healthcare professionals play important roles in parent vaccination perceptions and decision-making, this study addresses an important research gap by providing insight into the vaccination discourses and

practices of complementary and alternative medicine (CAM) providers. We open with a brief review on VH literature and CAM. We then evoke larger social and research narratives that tend to depict CAM providers and users as anti-vaccine advocates, which lays the groundwork for a discussion of the importance of considering choice, language, power dynamics, and legitimacy when researching CAM and biomedicine. Results from this study call into question such narratives and provide

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evidence showing nuanced CAM perspectives that go beyond the 'pro/' 'anti' divide. That said, results demonstrate how participants' discourses and practices diverge from biomedical and public health discourses on vaccination, particularly through their tendencies to individualize vaccination consultations and to place less emphasis on systematically adhering to official vaccination recommendations of the Swiss health authorities.

### 1.1. Complexities of vaccine hesitancy

Resistance towards vaccination is not new; when Edward Jenner proposed inoculation as a medical practice in 1797, it received mixed reactions, including rejection from colleagues, and took time before becoming standard practice (Riedel, 2005). We focus specifically on contemporary VH and agree with scholars who define *vaccine hesitancy* along a spectrum between anti- and pro-vaccination stances. It involves malleable attitudes whose underpinnings find roots in socio-medical trends which have been shaping healthcare landscapes over the past several decades (Peretti-Watel et al., 2015; Bedford et al., 2018). Such trends are multidimensional and linked to the notions of 'healthism' (Greenhalgh et al., 2004), risk culture (Beck et al., 1992), consumerism of healthcare (Tomes, 2001; O'Hara, 2013), patient autonomy (Armstrong, 2014), experiential and lay knowledge in patient decisions (Caron-Flinterman et al., 2005), mistrust of scientific expert advice, skepticism towards health authorities, and perceptions of pharmaceutical industry influence in scientific knowledge production and profit-seeking (Epstein, 1996; Benin et al., 2006; Salmon et al., 2015; Ward, 2017; Attwell et al., 2018a). Furthermore, with a general public health shift towards health promotion, which encourages people to take more responsibility and exercise more agency in health decisions (WHO, 1986), it is not surprising that the public and healthcare professionals have become proactive in questioning vaccinations. In other words, VH is not a stand-alone issue; it reflects larger social developments concerning health decisions.

Personal social networks can influence vaccine choices; the more vaccine hesitant people there are in one's network, the more likely one is to be vaccine hesitant (Brunson, 2013). The multitude of vaccine information, particularly via the press, social media, and the Internet, can lead to 'information overload,' 'misinformation,' and heightened levels of anxiety and indecision (Kata, 2010; Betsch et al., 2012; Yaqub et al., 2014; Wang et al., 2015; Sobo et al., 2016). Larson et al. (2014) systematically reviewed determinants of VH from a global scale, characterizing them as complex and context-specific, and concluded that there was "no universal algorithm" (p. 2155). Other scholars have also highlighted the need to clearly distinguish between (1) under-immunization as it relates to questions of access, affordability, logistics, and inadequate health systems, and (2) under-immunization as it relates to varying degrees of vaccine acceptance and non-acceptance (Bedford et al., 2018).

Another important vein of VH literature focuses on medical providers' influence on parents' decisions and emphasizes the importance of trust (Benin et al., 2006; Ames et al., 2017). Similar research highlights factors such as the time they spend on consultations and their information and communication styles (Kimmel et al., 2003; Bryant et al., 2009; Opel et al., 2012; Paterson et al., 2016). A conversation analysis of 111 consultations showed how providers who initiated discussions with *participatory approaches* (i.e. "What do you want to do about shots?") were more likely to be met with "resistance" than providers who initiated the discussion with *presumptive approaches* (i.e. "Well, we have to do some shots.") (Opel et al., 2013, p. 1037). Further analysis showed that providers' persistence with initially resistant parents brought about half of the parents to vaccinate, whereas the other half did not. Opel et al. (2013) concluded that additional research is needed, particularly involving shared decision-making between providers and parents. That said, there is evidence that motivational interviewing, a patient-centered communication intervention which invites individuals

to make decisions after exploring ambivalence, is effective in increasing vaccine uptake and reducing VH (Gagneur et al., 2018a, 2018b).

### 1.2. CAM, VH, and the vaccine narrative

Research efforts into VH have focused primarily on biomedical providers and tended to overlook, stereotype, or mystify CAM practitioners' roles regarding vaccination decisions. One study, for example, gathered evidence linking "anti-vaccination" and "pro-CAM" attitudes to "magical beliefs about health" (Bryden et al., 2018). Such an emphasis might be partially explained by larger cultural narratives. Sociologist Heller (2008) explains the tendency to scapegoat those who question "the vaccine master narrative" (p. 10) in which numerous scientific, medical, public health, and legal advances work in concert to frame vaccination as a champion of health for all, whereas non-compliers are considered "the opponent," characterized by ignorance and knowledge deficiencies (p. 14). He explains, "by insisting on universal compliance, the injunction to achieve one hundred percent vaccine coverage turns the small portions of the population who do not comply (for whatever reasons) into deviants who need to be cajoled into full compliance with vaccine policies" (p. 14).

Such narratives can be similarly exemplified by the difficulties encountered when attempting to clearly define CAM, which is perhaps best characterized through its diversity and contrasted relations to biomedicine. Researchers describe CAM as healing practices and modalities operating outside of, in addition to, or as accompanying biomedicine and accepted medical curriculum (Zollman et al., 1999; Wardle et al., 2016; Attwell et al., 2018a). Gale (2014) explains how language, through processes of defining and naming, serves as a vehicle for the power and legitimacy attributed to CAM and biomedicine, which underscores the importance of taking CAM providers' and users' experiences into account to understand such dynamics.

Social science research has demonstrated fundamental epistemological differences between CAM and biomedicine. Medical sociologists and anthropologists have argued that what counts as *evidence* for CAM practitioners and users differs from the oft-cited mantra of evidence-based biomedicine, where randomized controlled trials are considered the gold standard. Evidence in CAM, they argue, is expressed more in terms of experiential knowledge and embodied experience (Gale, 2010; Pedersen et al., 2010). Barry (2006) explains, "Non-biomedically trained alternative practitioners have a knowledge system that is closer to that of anthropology than to science-based medicine; it is more grounded in the phenomenal world of everyday lived and embodied experience" (p. 2655).

Qualitative studies have described what happens in CAM provider-patient interactions. A common theme among 46 Danish CAM users was that alternative medicine was 'risk-free' and that 'it could do no harm' (Pedersen, 2013). Another study from Denmark analyzed how trust, a key factor in vaccination decisions, is earned by practitioners of acupuncture, reflexology, and homeopathy through patient-provider relationships. "Practitioner's caring, careful listening and providing responsive feedback," (p. 54) their experiences of patients' bodies and patients' experiences of their own bodies, and the material experiences of the encounter were considered crucial (Pedersen et al., 2016). Furthermore, a study comparing CAM and biomedical approaches to patient-provider relationships in Germany found that practitioners of CAM were more likely to argue for shared-decision making with patients than biomedical general practitioners and insisted on "patient-centeredness" (Berger et al., 2012, p. 133).

Qualitative research on CAM and vaccination decisions is surprisingly scarce. A recent study from Australia describes how parents and CAM providers in two cities exemplified a *sybiotic* relationship regarding CAM and VH: "Vaccine hesitancy and CAM exist and function separately, but when combined, provide each other with 'resources' that enable them to thrive together" (Attwell et al., 2018a, p. 111). Results emphasized parents' preferences for natural approaches and

desires to exercise agency in immunization and healthcare decisions outside the influence of biomedicine and the pharmaceutical industry.

Quantification of CAM-use prevalence in Western countries, which use varying methodologies and definitions of CAM, reported rates of approximately 40% among adults in the US in 2007 (Barnes et al., 2008), 26% of the general population in Europe in 2014 (Kemppainen et al., 2018), and 40% in Germany and Switzerland, where a particularity is that CAM is often provided by medical doctors with additional CAM training (Hart, 2017). Studies seeking to quantify CAM use have additionally focused upon *why* people use CAM and show reasons including dissatisfaction with biomedicine, satisfaction with CAM encounters, alternative perspectives towards biomedicine, and interest in approaches combining CAM and biomedicine (Harris et al., 2012; Thomson et al., 2014; Leach et al., 2018). Additionally, CAM use correlates with higher levels of VH and with individuals who cite spirituality as an important source of information, exemplify intuitive (as opposed to analytic) thinking styles, and demonstrate openness to new experiences (Browne et al., 2015). Researchers in Australia found that children of parents who had consulted a complementary medicine (CM) practitioner were less likely to be up-to-date on their vaccinations than those who had not consulted a CM practitioner (Frawley et al., 2018). However, researchers have not determined causal pathways and explain associations in terms of confounding factors, such as higher income and education, or distrust of medical systems (Wardle et al., 2016).

### 1.3. The Swiss context

With around 8 million people and 3 distinct language regions (Swiss German, French, and Italian), Switzerland does not have any federally mandatory vaccinations in non-epidemic settings. The Swiss Federal Office of Public Health (FOPH) makes vaccination recommendations and communicates them to the public. Basic mandatory health insurance covers vaccination costs when the official schedule is respected and administered for at-risk groups for certain vaccine preventable diseases (VPD). With no federal mandate, vaccination programs are the responsibility of the 26 Swiss cantonal public health systems, and implementation modalities and coverage vary between cantons (Masserey Spicher, 2010; Lang et al., 2011a).

Vaccination rates in Switzerland are high overall (FOPH, 2015), and national coverage has remained stable or increased over the last twenty years (FOPH, 2018a). Regarding regional differences, children from the French and Italian-speaking cantons have on average higher rates of measles vaccination coverage than in German-speaking cantons (Lang et al., 2011b). Additionally, in 2017, the FOPH reported not systematically meeting targets: "Switzerland has only partially reached its objectives in terms of vaccination (...). For instance, flares of measles still occur in parts of Switzerland, taking advantage of locally low rates of vaccination" (FOPH, 2017, p. 5). Cases of measles, small epidemics (FOPH, 2009), and under-immunization tend to cluster around anthroposophic (i.e. Rudolf Steiner, Waldorf) schools and around certain CAM practitioners (Richard et al., 2009). However, the relationship between VH and immunization rates has not yet been extensively studied in Switzerland.

Research examining CAM in Switzerland show relatively high rates of use and favorable opinions among the population; Wolf et al. (2006) found that about 50% of the population had used CAM and about 50% of the population preferred hospitals with CAM therapies and providers. Data from the 2007 and 2012 Swiss Health Surveys have shown 25% CAM use in the population older than 15 years, higher probability of CAM use among those with chronic illness or poor self-perceived health, women, middle-aged people, and more highly educated individuals (Simões-Wüst et al., 2014; Klein et al., 2015). In Switzerland, CAM is often provided by medical doctors with CAM training (Hart, 2017). CAM services are reimbursed by basic mandatory health insurance when they are provided by medical doctors who have also

obtained additional postgraduate training in anthroposophical medicine, Traditional Chinese Medicine/acupuncture, homeopathy, or phytotherapy (FOPH, 2018b). Patients can choose to purchase supplementary insurance that covers other CAM-related costs that are not covered by basic mandatory health insurance; 60% of the adult population in 2012 reported having such insurance (Klein et al., 2015). CAM practitioners who are not medical doctors must undergo training and obtain accreditation in order to be eligible to receive payments through patients' supplementary insurance (ASCA, 2019; RME, 2019).

### 1.4. Study research questions

Considering the debated roles of CAM providers in VH and the popularity of CAM among large segments of the population, we consider it important to empirically study their views and practices regarding vaccination. Since vaccinations are not mandatory in Switzerland, healthcare professionals are allotted some leeway in their interactions with patients. Our study aims at understanding CAM providers' roles in VH and asks the following questions: (1) how do CAM providers describe their perspectives and roles regarding vaccination?; (2) in what ways, if any, do CAM providers' views and practices diverge from biomedical and public health vaccination discourses?; and (3) how do CAM providers and parents discuss vaccination during consultations?

## 2. Methods

We collected data in the French- and German-speaking regions of Switzerland (FR-CH and GE-CH, respectively) between August 2017 and November 2018. We conducted semi-structured qualitative interviews with CAM providers (N = 17) and ethnographic observations of vaccination consultations between providers and parents (N = 18 consultations with 5 providers). Practitioners were interviewed and then observed during consultations in an attempt at qualitative data triangulation; data gathered during interviews allowed comparison of their vaccination perspectives and descriptions of their interactions with parents to observations of what actually happened in practice during consultations.

The study was approved by the local ethics committee (*Ethikkommission Nordwest-und Zentralschweiz*). We recruited providers through research networks by sending recruitment letters and study flyers via e-mail, by personally calling potential participants, and through snowball sampling. Purposive sampling was conducted with providers' support to selectively observe consultations during which vaccination was likely to be discussed, including interactions with parents seen for the first time or with parents considering their children's first vaccinations. Informed consent was obtained from providers for interviews and from providers and parents for observations. Pseudonyms are used to protect the anonymity of participants.

BH, a pediatrician with training in anthroposophic medicine, and PET, an infectious disease specialist and internist, played important roles in recruiting participants. In total, we invited more than 50 CAM medical doctors and practitioners offering CAM. Not all responded. Eighteen declined to participate, with some citing concerns about our research agenda. A commonly expressed worry was that we were studying CAM and, by proxy, "anti-vaccine" practitioners, to use "their arguments" against them, with our team perceived as "pro-vaccine" or potentially "pro-mandatory vaccination." We clarified our research goals and explained our focus on understanding provider vaccination perspectives and experiences. Despite some providers declining to participate, to our knowledge, we were able to recruit and interview more CAM practitioners and observe more CAM vaccination consultations than other researchers in the past.

MD, a sociologist trained in qualitative methods, conducted 7 interviews and observed 10 consultations with 2 participants in FR-CH. JN, a medical doctor trained in qualitative research, conducted 8

interviews and observed 3 consultations with 2 participants in GE-CH. PK, a senior medical student with training in qualitative methods, conducted 2 interviews and 5 observations with 1 participant in GE-CH.

A qualitative interview guide was drafted based on VH literature, critically reviewed, and finalized after several iterations among research team members. The guide included open-ended questions for participants to answer in their own words and covered questions within the following themes: (1) providers' background and training, (2) parent-provider interactions during consultations, (3) perspectives on vaccination and immunity, and (4) perspectives on medicine and public health. The guide was tested prior to data collection. Interviews ranged from 47 to 110 min (average 70 min), were digitally audio-recorded, and transcribed verbatim.

Observed consultations were documented with ethnographic observation notes in field journals, which were subsequently written into a narrative format. In a semi-structured approach, we filled out observation guides that were created with the research team and based on VH and medical ethnography literature. These guides prompted researchers to document items of interest, such as the reason for consultations, the person who initiated the vaccination discussion, if the practitioner used presumptive or participatory approaches, which vaccinations were discussed, time spent discussing vaccinations, and researchers' interpretations of providers' and parents' emotions and communication styles.

After compiling interview transcripts and observation notes, several rounds of in-depth readings of the data, and discussions with the research team, a coding scheme was developed. The coding scheme allowed data to be coded into three main groupings: providers' (1) positions on vaccination along the spectrum of VH, (2) reflections on official Swiss vaccination discourse, evidence, and biomedicine, and (3) focus on individuals' choices.

Given the transdisciplinary nature of the team, our range of research backgrounds, professional experiences, and language abilities, we opted to analyze the qualitative data with the Framework Method described by Gale et al. (2013) with the support of MAXQDA software (VERBI, 2017). This allowed for structured flexibility in the sense that our guided interviews and observation approaches were informed by a *deductive* approach, meaning that our data collection tools were constructed based on VH literature. However, further analysis led us to adopt an *inductive* approach by incorporating themes into our analysis that emanated from the data. We therefore benefited from what Charmaz (2006) refers to as *constructivist grounded theory*.

Data were coded in the original language of utterance and then analyzed according to our coding scheme, with regular research team discussions throughout this process. These discussions allowed us to reflect on our interpretations of the data and to take into account how our backgrounds, knowledge, beliefs, and previous experiences may have affected the analysis of the results and our conclusions. We have translated supporting evidence, such as quotes from interviews, into English in this article.

### 3. Results

As shown in Table 1, we interviewed 7 providers in FR-CH and 10 in GE-CH. Of the 17 participants we interviewed, 15 were licensed medical doctors with additional training in CAM. In line with our approach inspired by constructivist grounded theory, we asked providers to explain the type of medicine they practiced in their own words. They reported practicing a range of CAM: 7 anthroposophic medicine, 7 homeopathic medicine, 1 Traditional Chinese Medicine/acupuncture (TCM), 1 phytotherapy, and 1 naturopathy. Such classifications are used heuristically. In reality, several providers described their practices as not fitting neatly into these categories; some practiced "integrative medicine," meaning they employ one or multiple CAM therapies in addition to biomedicine. We observed 10 childhood vaccination consultations in FR-CH and 8 in GE-CH with 5 practitioners. Consultations

concerned children ranging in age from 12 days to 8 years.

In the following sections, we draw upon findings from interviews with providers and observations of medical consultations. We first discuss CAM providers' nuanced positions on vaccination. Second, we describe how their tendencies to frame vaccination perspectives in terms of their and their patients' experiences serve as a point around which they articulated critiques of both biomedicine and biomedical vaccination discourses in Switzerland. Third, these discussions bring us to examine CAM practitioners' individualized approaches to vaccination discussions in clinical settings.

#### 3.1. CAM providers' nuanced views and practices on vaccination: going beyond the anti-pro dichotomy

Rather than having a categorical stance on vaccinations, providers demonstrated nuanced positions during interviews and observations and did not always express perspectives as being "pro" or "anti." Most participants reported favorable or ambivalent vaccine attitudes and regularly recommending vaccinations in practice. Furthermore, during interviews and observations, they discussed vaccination on a vaccine-by-vaccine, case-by-case basis, with the official Swiss vaccination schedule serving as a common reference point. Practitioners explained how they made a point to ensure parents were comfortable with their decisions, even if this meant not always adhering to official recommendations.

When discussing their sources of information on vaccination during interviews, providers cited medical journals, scientific sources, case studies, vaccination conferences, colleagues, Swiss vaccination recommendations, and books written for French- and German-speaking popular audiences. Several participants reported reading news sources to follow public debates and be informed about vaccination questions they might hear. Dr. Ferrand (FR-CH, homeopathic medicine) mentioned sometimes making a point of visiting controversial anti-vaccination websites, noting that it was "ridiculous," but justified doing this in order to remain up-to-date on "what is being said and to see the paradoxes."

Participants were not shy about expressing doubts and concerns related to risks of vaccination during interviews. Uncertainties varied and related to possible long-term negative effects of vaccines on children's immune systems, in particular the induction of autoimmune diseases, and unknown long-term effects of aluminum and other additives on the body, particularly the brain. One question concerned the "medical ecology," with a provider wondering, "Eradicating a disease makes space for what other disease?"

When deviating from official recommendations, which recommend the first vaccination at 2 months of age, providers reported delaying vaccines, often until 6-months of age, 1 year, or older, or not recommending certain vaccinations (for example: measles-mumps-rubella, poliomyelitis, hepatitis B, or human papilloma virus (HPV) vaccines). Opinions varied during interviews around polyvalent versus monovalent vaccines. Some practitioners reported encouraging polyvalent vaccines to avoid higher exposure to adjuvants over time, whereas others emphasized specific monovalent vaccines, such as the tetanus vaccine, in order to avoid "too many" vaccines at once.

Two providers professed to having strict anti-vaccination attitudes and being vocal about it with parents. Both are licensed doctors who practice homeopathy in GE-CH. Dr. Füssli explained that she never vaccinates children because, in her view, children are either too healthy and do not need vaccines, or they are too sick and cannot handle them. Dr. Kimmig, a doctor practicing in a small village, posited that if the public had all the information on vaccinations, people would not vaccinate. He reported not doing vaccine consultations and instead encouraged patients to attend vaccination evenings he hosts. At such events, he explains concerns about vaccine adjuvants, statistics showing that the prevalence of VPDs have diminished before the introduction of vaccinations, and how, in his own studies of approximately 200 of his

**Table 1**  
Characteristics of CAM provider participants.

Provider Pseudonym	Language Region	Type of CAM Practiced	Medical Doctor	Number of Consultations Observed
Dr. Heffelfinger	Swiss German	Anthroposophic medicine	Yes	1
Dr. Füssli	Swiss German	Homeopathic medicine	Yes	0
Dr. Welty	Swiss German	Anthroposophic medicine	Yes	5
Dr. Buchman	Swiss German	Traditional Chinese Medicine and Acupuncture	Yes	2
Ms. Krieger	Swiss German	Naturopathy	No	0
Dr. Abegglen	Swiss German	Homeopathic medicine	Yes	0
Dr. Kimmig	Swiss German	Homeopathic medicine	Yes	0
Dr. Pfyffer	Swiss German	Phytotherapy	Yes	0
Dr. Bär	Swiss German	Homeopathic medicine	Yes	0
Dr. Rüegg	Swiss German	Anthroposophic medicine	Yes	0
Dr. Laurin	Swiss French	Anthroposophic medicine	Yes	0
Dr. Schmidt	Swiss French	Anthroposophic medicine	Yes	5
Dr. Ferrand	Swiss French	Homeopathic medicine	Yes	0
Dr. Jansen	Swiss French	Homeopathic medicine	Yes	5
Ms. Beaulieu	Swiss French	Homeopathic medicine	No	0
Dr. Brescher	Swiss French	Anthroposophic medicine	Yes	0
Dr. Dupont	Swiss French	Anthroposophic medicine	Yes	0
N = 17			N = 18	

patients, vaccinated children had more allergies than non-vaccinated children.

The 2 providers not licensed as doctors, one a homeopath in FR-CH, the other a self-described naturopath in GE-CH, positioned themselves as ambivalent about vaccination during interviews. Neither saw their roles as being the primary person with whom vaccination consultations should take place. They instead viewed themselves as advisors who facilitated parents' decision-making. Both discussed their roles after vaccinations in "draining" undesirable vaccination components, such as aluminum or other adjuvants, from patients' bodies through homeopathic or plant-based remedies.

### 3.2. Intersections of experiential knowledge and evidence-based medicine: critiques of biomedicine and health authorities

Analysis of interview transcripts on providers' vaccination perspectives bring two summative themes to light: (1) CAM providers framed their perspectives in terms of their personal clinical experiences and patients' vaccination experiences; and (2) recounting such experiences allowed participants to express perspectives diverging from generally accepted biomedical consensus on health and illness. This section focuses on these themes while drawing from providers' political discourses on the Swiss context. Such discourses are political in the traditional sense, meaning that they refer critically to established health systems guiding medical conduct. They are also epistemologically political insofar as they deal with CAM providers' legitimacy in claims-making, particularly claims that question the *status quo* of the Swiss vaccination recommendation discourse.

The first theme primarily developed from providers recounting stories of their vaccination experiences in practice, with such accounts commonly introduced with phrases like, "In my experience," "a colleague told me," and "I know from experience." Participants occasionally invited us to take these stories with a grain of salt since they were uncertain that their experiences provided irrefutable evidence for or against vaccinations. As a case in point, Dr. Laurin (FR-CH, anthroposophic medicine) explained, "I know from experience that I have [patients] with less severe asthma. (...) Well, maybe it's due in part to other things." In contrast, Dr. Jansen (FR-CH, homeopathic medicine) framed favorable vaccination sentiment by explaining that the Swiss vaccination schedule was, in his experience, generally "well tolerated." Having worked in Swiss pediatric hospitals with cases of vaccine-preventable infections that were "often dramatic and very traumatizing," he voiced that it was "great" to be able to prevent children from getting

VPDs.

Some participants' ambivalence was reinforced by encounters with patients consulting specifically for vaccination due to patients' suspected adverse vaccine events. Over the years, Ms. Beaulieu, a homeopath in FR-CH, treated many patients who had reported developing adverse reactions after being vaccinated, which has had an important impact on Ms. Beaulieu's views. She explained, "There is what I think and what I see. And now, with 10 years of practice (...), I see that non-vaccinated children are sick much less. That is evidence, all the same!" Similarly, Dr. Dupont (FR-CH, anthroposophic medicine) was concerned about the large number of serious vaccine-related symptoms reported by patients he had seen throughout his career but recognized that his experiences were not representative: "Since my patients often come for a second opinion [for difficult cases], I see a lot of people who have had problems with vaccines. I have a deformed vision because of this." He admits, "There might not be a scientific correlation," but emphasized the importance of listening to "people who say, 'Listen, since I've had this vaccine, I don't feel well.'" He expressed a desire for "science" to take into account "what [these people] experience, [and] what they feel." Such providers expressed uncertainty whether these experiences with patients' purported adverse effects counted as enough evidence to question the merits of vaccination, meaning they remained open to the possibility that their views on vaccination were skewed, perhaps negatively, due to the types of patients who consulted with them.

The second theme dealt with CAM practitioners' criticisms of biomedicine. Many argued during interviews that illness is no longer tolerated in modern society due to its inconvenience. They added that biomedical providers were in a "panic" and "fearful" about diseases and infections. Participants generally expressed having a relaxed view about some vaccine-preventable childhood infections, with some arguing that we have "the right to be sick." Dr. Laurin (FR-CH, anthroposophic medicine) cited Rudolf Steiner, one of the founders of anthroposophic medicine, when arguing in favor of developmental advantages of childhood illnesses: "Children transform their bodies into what they need through their childhood illnesses." Dr. Dupont (FR-CH, anthroposophic medicine) echoed this sentiment, contending that since the 1990s, measles had become a socially unacceptable disease, stating, "We didn't use to make such a monster out of it." Dr. Kimmig (GE-CH, homeopathic medicine) advocated for parents having the possibility to introduce certain diseases to their children, "I always say that we should set up a rubella-hotline. If you have a 5- or 6-year-old daughter, you can call, 'Hey, is there someone with rubella around here?' Then

you can go there for a visit, maybe she'll get infected." Such perspectives considered certain childhood illness as developmental milestones that vaccination might impede.

Participants' vaccination discourses were also shaped by contexts in which they practiced medicine. When discussing vaccination necessity in Switzerland during interviews, providers generally constructed Switzerland as a safe space. Several activated epidemiological evidence to argue that the risk of contracting certain VPDs, such as poliomyelitis, was virtually null in Europe and Switzerland. They also noted how they accepted treating non-vaccinating parents who stayed within their communities and limited possible exposure to VPDs. In contrast, some providers recommended vaccination to parents who planned to travel outside of Switzerland. Dr. Buchman (GE-CH, TCM and acupuncture) alluded to the potential infectious *Other* by explaining to a mother during a consultation observation that there were cases of polio in "Egypt, Nigeria, and similar countries, but if you don't have contact with people from those countries or travel there, the risk of contracting polio in Switzerland is very small." Dr. Laurin (FR-CH, anthroposophic medicine) argued that the Swiss medical system was adequately prepared to handle tetanus infections but that its low prevalence might actually impede younger doctors from detecting it: "If the wound is suspicious, most doctors no longer know how to recognize possible tetanus infections."

Given the attention participants attributed to possible negative consequences when following official vaccination recommendations, providers expressed interest during interviews in having the Swiss FOPH clearly state potential health risks of vaccines to the public. Dr. Ferrand (FR-CH, homeopathic medicine) explained this being an important knowledge gap, citing "bias" in the presentation of information:

(...) the FOPH's information is really good. But, when it comes to some of the grey areas, we find ourselves in a type of magma of information that is very, very difficult to sift through. We kind of have the impression that the FOPH and the Vaccination Commission only shows studies that are [unfinished sentence]. There are studies showing there are maybe complications. Scientific honesty would have it so that those studies are also shared so that we could have that specific element. As a result, we must look further than what the FOPH tells us.

Along these lines, other providers alleged there being a lack of clear scientific consensus in Switzerland before the implementation of new vaccination recommendations. Dr. Abegglen (GE-CH, homeopathic medicine) expressed disappointment in the implementation of the MMR vaccination recommendation, "there were doctors who had clearly spoken against the MMR vaccine, across all fields, not only from complementary medicine. I found it a pity that they just decided to do it that way and pushed it through."

Similarly, a recurring point of contention concerned mandatory vaccinations, which was *à propos* due to Switzerland's geographical proximity to, and cross-cultural influence with, France, Italy, and Germany, where vaccine mandates have been intensely debated and, in some cases, implemented, in recent years. Dr. Schmidt (FR-CH, anthroposophic medicine) commented:

It's clear that for many vaccines, it's to have herd protection, or herd immunity. The decision is much larger than the child alone. That said, I think that it should be a free choice for the parents to decide. It's only if the diseases really pose a consequential public health risk that we can start thinking about mandatory vaccinations. That's why I think the political decisions in Italy and in France are not at all justified.

Dr. Ferrand (FR-CH, homeopathic medicine) argued in favor of a "personalized" approach "rather than mass vaccination programs that have not been properly thought through." Dr. Laurin (FR-CH, anthroposophic medicine) cogently encapsulates these sentiments through his direct criticisms of mass vaccination programs and mandates: "We now

know that there are not two individuals who are exactly the same. However, for me, vaccination comes from the practice of veterinary medicine. They're now referring to us as herds! (...) That's not human medicine for me, especially when it's practiced in a mandatory way."

In other words, CAM providers' discourses depict them as *treating humans, not herds*, a sentiment which succinctly summarizes their discourses and practices. Providers were acutely aware of political implications of openly questioning vaccinations. Dr. Laurin (FR-CH, anthroposophic medicine) explained, "Being against vaccination in a university setting is a career killer!" Despite perceived taboos within established biomedical settings, participants were comfortable positioning themselves as reflecting critically about vaccination for individual patients. The core of providers' reflections was that uniform vaccination programs might not be justified because they fail to meaningfully take into account CAM perspectives, evidence from clinical experiences, and individual patients' contexts and wishes.

### 3.3. Emphasizing individualized choices

CAM providers' approaches to vaccination focused on individual patients, families, and their specific social contexts and did not involve actively pursuing public health objectives related to herd protection. They employed individualized approaches by incorporating: (1) parents' pre-existing knowledge and perceptions on vaccinations and vaccine-preventable diseases, (2) parents' wishes and concerns, and (3) patients' histories, physical constitution, medical history, and social and family contexts. During interviews, CAM providers explained their roles in vaccination consultations as consisting of "informing parents," "encouraging the families to take responsibility for vaccination choices," "accompanying parents in their choice," "listening to parents," and "not being judgmental or prescriptive."

The following paragraphs result from the combined analysis of interview data and observations of medical consultations, allowing us to compare what CAM practitioners said to what they did. Both in their descriptions and in practice, providers emphasized the importance of establishing parents' perceptions and knowledge-base on vaccination and VPDs as a starting point. Dr. Ferrand (FR-CH, homeopathic medicine) explained:

We first speak about vaccines generally. Then, I go over them one by one. And for each one, I ask [the patients] what types of information they had sought out. What information do they already have? What are their concerns about vaccinations? (...). I tell them the FOPH recommendations. Then, I tell them my information.

An extract from field notes from an observation with Dr. Schmidt (FR-CH, anthroposophic medicine) reflects the approach described by Dr. Ferrand.

Dr. Schmidt paused and asked the parents if they had considered vaccination for their son. The mother, a law student, laughed nervously and whispered that they were "anti-vaccine." The father, a medical doctor who also practices Ayurveda, explained how his thinking about vaccines originally aligned with biomedicine and that he used to think that vaccination was the best option. He recounted how he and his wife had read "an excellent book," *Qui aime bien, vaccine peu* [rough translation: *Those who love [their children] vaccinate little*], which had led them to change their minds to thinking they could "go without vaccination." Dr. Schmidt nodded, showing that he knew the book and said that the book was "a bit harsh" toward vaccines.

Participants thematically referred to parents' "wishes," "choices," "options," and "preferences" when discussing vaccinations during interviews and observations. Such "choice talk" is supported by the political option to not vaccinate in Switzerland in accordance with non-mandatory FOPH recommendations. Dr. Schmidt (FR-CH, anthroposophic medicine) emphasized the importance of choice, stating his

goal was to “recommend normal vaccinations, according to the Swiss schedule,” but that it was “the parents’ choice,” that they sometimes have “different preferences,” and “wish to vaccinate less or later.” He found it “important” to “find something that is adapted to the parents.”

Observations with Dr. Buchman (GE-CH, TCM and acupuncture) provided insight into how providers individualized the discussion. Observation notes report the following with a hesitant mother of a 2-year-old daughter. The consultation lasted 55 min, 50 min of which were attributed to vaccination:

The mother nodded and took out two sheets of paper covered in handwritten notes (...) The mother said that she was unsure if she should vaccinate her daughter and that her husband knew some people who said they had been harmed by vaccinations. They were not sure if this was true, but it made her have doubts. She said she was generally a fearful and careful person, so hearing things like that from her husband’s friends scared her. (...)

Dr. Buchman said she was not against vaccinations but preferred alternative schedules. She also stated that she did not vaccinate during the full moon, or two days before or after, and that she always tested vaccines “kinesiologically” before administering them.

Dr. Buchman then personalized the discussion by considering “kinesiology reactions.” With the daughter in the mother’s lap, the doctor applied pressure to the mother’s arms, held at a 90° angle, while her daughter held the vaccine-containing syringes. If the mother’s arms dropped, it meant that the daughter would not tolerate the vaccine. Her arm dropped slightly for the *Infanrix*® vaccine (diphtheria-tetanus-pertussis-poliomyelitis-haemophilus influenzae type B) but not *Boostrix*®-Polio (diphtheria-tetanus-pertussis-poliomyelitis). Dr. Buchman concluded that the mother should elect for *Boostrix*-Polio if she chose to vaccinate.

CAM providers adapted vaccination discussion to families’ specific social milieu for context-specific recommendations. They sought to gauge relative risks of exposure to VPD and parents’ abilities to take care of their child in cases of illness. For example, in this excerpt from observation notes, Dr. Schmidt (FR-CH, anthroposophic medicine) discussed vaccines for the 2-month-old son of a 26-year old mother, a primary school assistant:

The mother spontaneously brought up vaccinations. Seemingly apprehensive and hesitant, she explained, “For vaccines, we will do only the most basic ones. I prefer waiting, and I only want the most important ones.” She was unsure which ones were most important and asked for recommendations.

Dr. Schmidt asked if the son went to a nursery. She said that she did not intend to send him. The doctor began explaining the Swiss recommendations, stopping to ask the mother if she had female friends with children. She said that there were no children in her social entourage and that she always asked friends to disinfect their hands before holding her son. The mother glanced at the schedule and asked about minimum recommendations. He explained that it was difficult to determine and that it was her choice: “It’s up to you to decide.”

CAM providers considered patients individually without actively pursuing public health goals of herd immunity and disease eradication with the common thread tying their approaches together being how they put the parents’ contexts, concerns, and wishes at the center of the discussion. Dr. Welty (GE-CH, anthroposophic medicine) explained during an interview, “The most important thing for me in the end is not what you vaccinate, or if you vaccinate, but the decision-making path.” Most providers reported following up with non-vaccinated children at later consultations to see if parents had changed their minds or reflected further. During interviews, participants reported pointing out the potential for social exclusion and disapproval toward parents brought about by non-vaccination, explaining that such a choice might not be

socially acceptable in certain daycare centers, hospitals, or schools. We also witnessed similar explanations about potential social exclusion during consultation observations. Several providers argued that having healthcare professionals who accept non-vaccination or hesitancy might do families a favor. They explained that through their acceptance of these parents, they could build better rapport and perhaps lead to later vaccination. Dr. Schmidt (FR-CH, anthroposophic medicine) explained, “I have the impression that if we take the time and explain it well, the majority will end up vaccinating. Maybe they vaccinate less, but we can still get them vaccinated.”

#### 4. Discussion

CAM providers’ willingness to not systematically adhere to Swiss vaccine recommendations might partially frame them as opponents in the vaccine narrative described by Heller (2008). The majority of the evidence we gathered, however, calls anti-vaccination CAM provider stereotypes into question. Participants were overall ambivalent or favorable towards vaccination and had nuanced, context- and vaccine-specific views, despite being markedly aware of the social consequences of questioning vaccination, with the example of Dr. Laurin (FR-CH, anthroposophic medicine) recognizing that questioning vaccination can be a “career killer.” However, providers’ doubts about vaccinations for all patients stemmed from their expressed desires to consider each patient individually. Practitioners also took their previous clinical experiences and patients’ suspected adverse vaccine events into account as evidence to be weighed in vaccination reflections. The inclusion of experiential evidence into CAM providers’ considerations for clinical practice and recommendations raises larger epistemological questions about the role of evidence, and the legitimacy of different types of evidence, in patient-provider interactions.

Through their qualitative work on CAM users, Attwell and colleagues (2018) defined CAM users’ and providers’ relationships with each other and to vaccine hesitancy as *symbiotic*. Our findings support their argument that parents and CAM providers “provide each other with ‘resources’ that enable them to thrive together” (p. 111). Our results, particularly from ethnographic observations of vaccination consultations, highlight the importance of patients’ ability to exercise agency in vaccination decisions, with providers seeking to enhance this agency by inviting parents to actively partake in decision-making. Providers’ roles were not prescriptive; rather, they acted as medical advisors who informed and encouraged parents to take responsibility for their choices. This echoes what Dubé et al. (2013) found when comparing medical doctor and midwife roles in vaccine discussions in Quebec; doctors adopted “education-information” stances to “convince” parents, whereas midwives adopted a “neutral stance” by informing patients of the advantages and disadvantages while leaving the decision to the parents (p. 242). Research in other settings has likewise found that midwives emphasize parental choice and neutrality during vaccination consultations (Pearce et al., 2008; Attwell et al., 2018b).

The literature on provider communication about vaccination is not uniform. While some researchers have documented that adopting a presumptive communication style with parents is associated with increased vaccination uptake (Opel et al., 2013), others have documented that trying to convince patients often-times backfires, as such communication can be perceived as condescending, belittling, or patronizing (Ball et al., 1998; Kahan, 2013; Nyhan et al., 2014; Masaryk et al., 2016).

With the message that CAM providers *treat humans and not herds* emanating from our data, it is tempting to castigate them as adversaries to public health goals of preventing spread of disease. Brunson et al. (2017) urge us, however, to “get past” polarized visions on vaccination to further understand the multidimensional aspects of vaccination decision-making. Although the CAM practitioners in our study may not have proactively pursued official vaccination recommendations, many argued that continued investment of time and effort with parents

eventually led to vaccination. Through their engagement in dialogue with parents over time, providers undertake work that assuages some of the more complex determinants of VH related to augmenting patient agency, such as parents' adherence to 'healthism' (Greenhalgh et al., 2004), healthcare consumerism (Tomes, 2001; O'Hara, 2013), and parent autonomy in decision-making (Armstrong, 2014). The caveat is that, depending on one's epistemological stance on what counts as evidence and informed decision-making, CAM providers' willingness to stray from recommendations through individualization could potentially bring parents to make decisions leading to illness through non-vaccination.

Our results call us to further consider the role of individualized healthcare in vaccination discussions, which aligns with other current medical and public health efforts. Such measures are currently in vogue and seek to bring individualized, personalized, and patient-centered approaches to the forefront of healthcare (Tutton, 2012; Rose, 2013; Holt et al., 2016; Evangelatos et al., 2018). Gofen et al. (2015) analyzed healthcare professionals' discourses around personalized approaches to vaccination noncompliance in Israel and noted how "personalization appears to be a 'quick fix' to increase compliance," but cautioned that public health practitioners "may be further undermining the broader argument that vaccination can be safely administered as a standardized intervention, and discrediting the notion of a public duty to uphold herd immunity" (p. 278). Furthermore, a systematic review on vaccine hesitancy and communication showed that individualized, participatory formats might be preferable in clinical practice but concluded that more work was needed (Connors et al., 2017).

Since vaccination programs rely upon high compliance for success in terms of herd protection, individualizing the approach might seem counterproductive. However, framing public health efforts to address VH (and not solely on rejection or compliance) for the minority of parents who are vaccine hesitant recognizes how VH determinants are linked to larger questions of patients' trust of healthcare professionals, expert opinion, advice and authority, and perceptions of the influence of financial interests in science. As such, discussions can be conducted in ways that are individually meaningful to vaccine hesitant patients.

From a public health perspective, this argument might not be an easy pill to swallow because it moves away from the prevalent *one-size-fits-all* approach, which is how vaccination has historically been framed. Addressing *vaccine hesitancy* and addressing *diminishing immunization rates* might not always be the same thing and may require different tools. Efforts could therefore be tailored towards vaccine hesitant individuals in clinical practice in order to address specific concerns. Rather than focusing on the epistemic divide between CAM and biomedicine, which has been documented here and elsewhere, we propose that efforts to address VH and improve patient care, for that matter, can revolve around areas where CAM and biomedicine can agree. Both will likely find common ground concerning improved patient communication and relationships.

Larson et al. (2014) argue that multidisciplinary approaches, which are "broad in scope but context-specific," (p. 2156) are necessary to understand the underlying factors of VH. Our qualitative results provide insights specific to Switzerland but with potential implications for other high-income countries, where research and patient interest in CAM is high (Italia et al., 2014; Hart, 2017). We should nonetheless be cautious in generalizing our findings. Our sample size of 17 CAM-oriented providers was composed of voluntary participants. Their participation and generally favorable or ambivalent vaccination views might result from a vested interest in vaccination and more thought-out perspectives than those of presumably more vaccine-hesitant or vaccine-opposed providers who declined to participate. While our approach to observe vaccination consultations was innovative and revelatory, this method can pose specific challenges, such as seeking approval from both parents and providers before the observations begin, which can disrupt the natural flow of patient-provider interactions. Additionally, the presence of a researcher in a consultation room might be perceived as intrusive

and potentially influence the ways participants interact. Finally, our sample was heavily represented by CAM providers trained as medical doctors, which seems to be a particularity of CAM in Switzerland (Hart, 2017). Future work should involve wider ranges of CAM perspectives and would benefit by focusing on patient-provider relationships and interactions.

## 5. Conclusions

Our study provides important novel insights into vaccination consultations with CAM providers in Switzerland. To our knowledge, such firsthand data on CAM practitioner discourses and practices regarding vaccinations, particularly combining qualitative interviews with ethnographic observations of consultations, have not been documented in the literature. This triangulation of qualitative methods allowed us to discuss CAM providers' discourses about their experiences and perspectives (i.e. what they said) in relation to their practices *in situ* (i.e. what they did), which both demonstrated their individualized approaches to vaccination in consultations.

Additional research could benefit from considering patient use of CAM, biomedicine, and VH on a larger scale. In addition to gathering socio-demographic information and other drivers of VH and under-immunization, further studies could include variables demonstrated as being consequential to parents, such as exercising agency in healthcare decisions, trust in medical authority, and satisfaction in patient-provider interactions. Future research could also explore emulating how CAM providers engaged with parents in this study; they established parent knowledge and views on vaccination, included parent wishes and concerns, and incorporated patients' health and social contexts into vaccination discussions. Undertaking such efforts might not be easy. Establishing trusting relationships between patients and healthcare providers in clinical settings takes time, resources, and communication training and may benefit from policy maker support in encouraging incentives for providers to engage in lengthier consultations. We argue that engaging vaccine hesitant patients in such a way can improve both vaccine communication and patients' experiences in healthcare encounters by activating patient agency in vaccination decisions.

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## Chapter 4

# 'Problem patients and physicians' failures': What it means for doctors to counsel vaccine hesitant patients in Switzerland

### Notes

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## 'Problem patients and physicians' failures': What it means for doctors to counsel vaccine hesitant patients in Switzerland

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### ABSTRACT

This article reports on our qualitative inquiry into the meanings biomedically trained doctors in Switzerland attach to treating vaccine hesitant (VH) and underimmunized patients. With support from social science literature on 'good' and 'bad' patients and doctors, we explore how both doctors and patients cross the boundaries of these conceptual categories in situations involving vaccine hesitancy and underimmunization. The doctors we interviewed (N = 20) and observed (N = 16 observations, subsample of 6 doctors from the interview sample) described how they screened, measured, and diagnosed patients' levels of vaccine hesitancy. Our results emphasize the meanings doctors associated with counseling hesitant patients, especially while managing their own professional responsibilities, legitimacy, and reputations among colleagues and patients. Doctors' discourses constructed the figure of 'problem patients,' characterized through their (potential) non-adherence to vaccination recommendations, desire for lengthy consultations and individualized counseling, and dogmatic ideologies running contra to biomedicine. Discussions around the dilemmas faced by doctors in vaccination consultations brings to the fore several key, yet underdiscussed, paradoxes concerning VH, patient-doctor relationships, and the constructs of 'good'/'bad' doctors and patients. These paradoxes revolve around expectations in Western societies for 'good' patients to be autonomous health-information seekers and active participants in clinical encounters, which research shows to be the case for many VH and underimmunizing individuals. However, in the eyes of many vaccination advocates and proponents of biomedical approaches, VH patients become 'bad' patients thru their risk of non-adherence, which has implications for the population at large. In these consultations, doctors find themselves conflicted around the expectations to promote vaccination while, at the same time, being active listeners and good communicators with those who question their biomedical training and legitimacy. Understanding these paradoxes highlights the need to better support HCPs in addressing VH in clinical practice.

### 1. Introduction

"During my training, the idea was implicitly there that we shouldn't have people who are against vaccination in our offices, almost as if it were a failure of the pediatrician. It was like having problem

patients. I would say to [these patients], 'Listen, that's not OK.' I was more judgmental. (...) After a few years, I became more interested because I realized that these people were much more vigilant when it came to health than the average person. Then, auto-didactically at first, I realized that my role as a doctor was to respect patients in

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their entirety. It's not because they refuse something that I can't be their doctor anymore. My colleagues would always criticize me. I would tell them, 'If I was an oncologist and a patient refused chemotherapy, 'It's ok!' I can still be their doctor. It's not because they refuse chemotherapy that I have to throw them out.'" (Dr. Caspari, pseudonym)

In this statement, Dr. Caspari, a pediatrician from the French-speaking region of Switzerland, covers several of the issues that this article touches upon: (1) how doctors classify patients based upon vaccination attitudes and behaviors, (2) dilemmas doctors face when seeing vaccine hesitant (VH) patients, and (3) how doctors' willingness to accept these individuals has repercussions for their reputations as doctors intraprofessionally and with patients. Drawing upon data gathered from qualitative interviews with medical doctors and observations of vaccination consultations in Switzerland, we argue that the dilemmas doctors face in situations involving vaccine hesitancy (VH) often arise from paradoxical expectations inherent to the social constructs of 'good' and 'bad' patients and doctors.

As we will demonstrate, the constructs of 'good' and 'bad' patients and doctors are inherently problematic when it comes to VH. VH patients tend to demonstrate characteristics of 'good' patients insofar as they proactively seek health information and participate in consultations. However, through their potential nonadherence, they transgress the bounds of acceptable patient behavior. Conversely, 'good' doctors are expected by public health authorities to pursue vaccine recommendation adherence while maintaining communication with patients whose rationales may contradict their medical training and biomedically institutionalized recommendations.

We begin by providing a brief review of literature into vaccine hesitancy and under-immunization. We next describe the important roles healthcare professionals (HCPs) play in influencing patients' attitudes and behaviors around vaccination. Then, we tie these discussions into conceptual understandings of 'good' and 'bad' doctors and patients, which lays the groundwork for understanding the paradoxes of norms that patients and HCPs have internalized in relation to vaccination decision-making in Western societies. We conclude the introduction section with information on the Swiss context, where complementary and alternative medicine (CAM) use is popular and often discussed relationally to biomedicine. This qualitative research was conducted in the context of a larger Swiss National Research Program focusing on both routine childhood vaccinations and the human papillomavirus (HPV) vaccine (Deml et al., 2019a).

### 1.1. Vaccine hesitancy: A "threat" to global health

In early 2019, the World Health Organization listed VH among one of ten important threats to global health. The announcement called attention to a recent 30% increase in measles cases globally and the importance of healthcare professionals (HCPs) as "the most trusted advisor and influencer of vaccination decisions," who need to "be supported to provide trusted, credible information on vaccines" (WHO, 2019).

The Strategic Advisory Group of Experts (SAGE) Working Group on Vaccine Hesitancy defined VH as a "delay in acceptance or refusal of vaccination despite availability of vaccination services" (MacDonald, 2015, p. 4146). Scholars have criticized this definition, pointing out (1) the presentation of VH as a behavior (i.e. delaying or refusing certain or all vaccines), whereas hesitancy is a "psychological state" (p. 6566), (2) hesitancy is used as an umbrella term that incorrectly includes those who categorically choose not to vaccinate, and (3) hesitancy can be erroneously used as a causal explanation for underimmunization, while other determinants of health, such as pragmatics, access barriers, and inadequate services or policies, may play a larger role in vaccine uptake (Bedford et al., 2018).

Others contend that VH is an ambiguous notion, stating its common

usage does not always take into account larger socio-medical trends. Peretti-Watel et al. (2015), for example, propose a theoretical framework which "considers VH a kind of decision-making process that depends on people's level of commitment to healthism/risk culture and on their level of confidence in the health authorities and mainstream medicine" (p. 2). Additionally, understanding VH from a global perspective poses methodological challenges because "[d]eterminants of vaccine hesitancy are complex and context-specific—varying across time, place and vaccines" (Larson et al., 2014, p. 2150). It is therefore important to specify our consideration of VH in Switzerland, which is a rich country situated in the heart of Western Europe.

We acknowledge these subtleties and pragmatically define *vaccine hesitancy* as attitudes expressing concerns, worries, and skepticism about the safety, efficacy, or necessity of vaccination. We define *underimmunization* as the behavior of not adhering to the Swiss vaccination schedule (FOPH, 2019) by omitting or delaying some or all of the recommended vaccines.

### 1.2. Healthcare professionals and vaccine hesitancy

The roles HCPs and doctors in particular play in influencing patients' vaccination behaviors and attitudes have been well documented in public health and medical literatures (Opel et al., 2013; Verger et al., 2015). Important factors include providers' knowledge, attitudes, behaviors, communication styles, and information sources (Opel et al., 2012; Paterson et al., 2016). A key factor influencing patients' vaccination decisions is trust in the provider (Ames, 2017). For example, Benin et al. (2006), through analysis of 33 qualitative interviews with mothers, explain how trust in providers is a main determinant in vaccination decisions: "Mothers identified as more trustworthy those relationships in which their providers expressed a passion about vaccination, seemed knowledgeable, were able to offer satisfactory answers to questions that were asked, did not act condescending or rushed, and treated them like an individual" (p. 1539).

Recent VH literature focuses on building vaccine confidence and lowering hesitancy among HCPs. MacDonald and Dubé (2015), for example, note that "many healthcare providers are themselves vaccine-hesitant and therefore unlikely to dispel their patients' concerns and doubts about vaccinations" (p. 792). This commentary responded to a study showing 43% of GPs in France sometimes or never recommended at least one vaccine to target patients. GPs who made vaccine recommendations, compared to those who did not, were more comfortable explaining benefits and risks and reported having more trust in official sources of information. This suggests that GPs' knowledge on vaccination benefits and risks could be reinforced (Verger et al., 2015). Manca (2018), through qualitative interviews with doctors and nurses in Canada, found that despite general support for vaccination, HCPs expressed anxieties about specific vaccinations, pharmaceutical company influence, vaccine novelty, and limitations of biomedical knowledge.

Common concerns faced by HCPs when addressing VH have also been reported. Although not a recommended practice (Gilmour et al., 2011), doctors sometimes dismiss families from their practices due to parental vaccine refusal, justifying dismissals by citing fear of litigation and lack of shared goals and of perceived trust from patients (Flanagan-Klygis et al., 2005; O'Leary et al., 2015). Another trend pediatricians face involves parents requesting to delay vaccinations or to follow alternative vaccination schedules (Wightman et al., 2011).

Researchers have examined job satisfaction among doctors who regularly counsel patients about vaccination. A survey among a nationally representative sample of pediatricians and family medicine doctors in the US showed that pediatricians were more likely to cite lower job satisfaction when addressing vaccination concerns and questions and to perceive a lack of respect toward their medical judgement in disagreements over vaccine recommendations (Kempe et al., 2011). Forty percent of pediatricians and family doctors in a similar US

study reported lower job satisfaction due to requests to delay vaccinations, 82% felt that agreeing to delay vaccines could build trust, and 80% responded that families might leave their practices in cases of disagreement (Kempe et al., 2015).

### 1.3. Patients and doctors: the good and the bad

We draw upon the surprisingly underdeveloped sociological literature concerning doctors' subjective constructions of 'good' and 'bad' patients and upon similar literature concerning patient and HCP perspectives on what constitutes 'good' and 'bad' doctors. Whereas such distinctions are admittedly reductive, they are conceptually useful in delineating doctors' expectations of patients in vaccination consultations and vice-versa.

Although the previous discussion highlights difficult situations doctors face concerning VH, it does not provide detailed understanding into their experiences with VH and unvaccinated patients. However, one notable study from the US evaluated pediatric resident and medical student reactions to 3 imaginary scenarios in which parents of one-year-olds questioned evidence-based recommendations: parents (1) requesting unnecessary antibiotics for a viral infection, (2) considering tympanostomy tubes for recurring ear infections, and (3) hesitating about vaccination (Philpott et al., 2017). Participants assigned to the VH group were significantly more likely to consider "the parent as difficult, saw less value in the conversation, and had lower respect for the parent's views" (p. 1701), and 41% of VH group participants indicated they would be pleased if VH parents did not return to their clinic.

Doctors' subjective perceptions of their patients are not trivial matters. Street et al. (2007) examined doctors' perceptions of patients and communication styles in a study involving doctors and patients from 10 US outpatient settings. They explained that "physicians were more patient-centered, less contentious, and showed more positive affect to patients they judged to be better communicators, more satisfied with care, and more likely to adhere to treatment" (p. 594). With conceptual support of research from Jaye et al. (2006), Hafferty and Hafler (2011), and Higashi et al. (2013) into students' internalization of the 'hidden curriculum' of medical school, Sointu (2017) conducted qualitative interviews with medical students undergoing clinical rotations in the US. She provides convincing evidence showing how such internalizations shaped their sense of patient worth and the distinction between 'good' and 'bad' patients. 'Good' patients are described as good communicators, knowledgeable, compliant with doctor recommendations, active participants in decision-making, interesting, and individuals with whom doctors can empathize and identify (Higashi et al., 2013; Sointu, 2017). In contrast, 'bad' patients have been defined through their non-compliance with doctor recommendations, questioning of HCP legitimacy and authority, lack of knowledge, and being difficult or problematic (Jefferey, 1979; Wright and Morgan, 1990; Higashi et al., 2013; Sointu, 2017).

From a public health perspective, patient adherence to official vaccination recommendations is a major consideration in vaccination consultations because high levels of compliance are required for immunization programs to be effective at population levels. Doctors are therefore expected to achieve high levels of patient adherence to vaccination recommendations. For example, Brownlie and Howson (2006) describe how HCPs perceive their professional responsibilities and engage in "governing health at a distance" (p. 433) by taking public health targets into account during vaccination consultations.

Patient nonadherence has traditionally been understood within the framework of the knowledge deficit model (Lawrence et al., 2014; Kitta and Goldberg, 2017), wherein the assumption is that nonadherence is due to patients' irrational behavior and/or lack of sufficient knowledge. However, medical sociologists and anthropologists have argued that nonadherence can be reframed as irrational in the eyes of medical experts and as rational from patients' perspectives (Donovan and Blake,

1992; Bury, 1997). Research has also shown that appropriate communication from physicians is correlated with higher treatment adherence among patients and that physicians who communicate poorly have higher risk of patient nonadherence to recommendations (Zolnieriek and Dimatteo, 2009).

Social science literature on the subject of 'good' and 'bad' doctors revolves primarily around the issue of communication. A study involving 60 laypeople in Australia found that patients constructed 'good' doctors by emphasizing doctors' communicative abilities, interpersonal skills, ability to listen, willingness to spend time with patients, compassion, empathy, and how much patients could trust them (Lupton, 1996). Interestingly, most participants considered doctors' interpersonal skills to be more important than their medical knowledge and expertise. Participants described 'bad' doctors as viewing patients like they were on a "production line" (Lupton, 1996, p. 160), not having enough time, hurried, and not listening to patient concerns or questions.

In a follow-up study with 20 doctors in Australia, Lupton (1997b) describes how doctors, like the patients described above, also underscored the importance of communication. Doctor participants described how 'good' doctors "should be able to draw patients out, to listen to their concerns and to translate medical jargon into terms that patients can easily understand" (p. 488). Participants further argued that doctors should be empathetic and able to understand patient perspectives. In contrast, they described 'bad' doctors as dishonest, bad listeners, patronizing, or having purely financial interests. Such understandings underscore the importance of affect (i.e. how people feel) in clinical encounters, especially when individuals may favor the emotional elements of their experiences with HCPs over the medical expertise and knowledge HCPs might offer (Lupton, 1997a; Navin, 2015). It is important to note that doctors also recognized the roles of their own feelings and affect in clinical encounters in the above-discussed literature.

Lutfey (2005) combines the concepts of adherence and 'good doctoring' in an ethnographic analysis of two diabetes clinics in the US. From HCP perspectives, she argues that by pursuing patient adherence to medical recommendations, HCPs take on multiple roles: educators, detectives, negotiators, salesmen, cheerleaders, and policemen. She further argues that the goal of persuading patients only "superficially appears to dismantle the paternalism of traditional physician roles" (p. 423). In other words, when patient adherence is HCPs' desired primary outcome, they struggle to effectively engage in true shared decision-making.

### 1.4. The Swiss context: biomedicine and CAM

Participants' professional reputations and identities are embedded within the broader Swiss context, where complementary and alternative medicine (CAM) use is prevalent among 25–50% of the population (Wolf et al., 2006; Klein et al., 2015). CAM use has been associated with VH and underimmunization in other high-income countries, and this association is complex, multifaceted, and merits further study (Wardle et al., 2016). In 2009, the Swiss populace voted through a constitutional referendum to integrate CAM into its healthcare system by, among other aspects, including its reimbursement through basic mandatory health insurance (Saller, 2009; Debons, 2015). Given the popularity of CAM in Switzerland, medico-professional perspectives on vaccination are inscribed into contexts in which the authority of CAM and biomedicine is oftentimes expressed relationally. This article complements our previous qualitative research into CAM and VH in Switzerland (Deml et al., 2019b) by here focusing on how medical doctors who do not practice CAM address VH in clinical practice.

### 1.5. Research questions

With the goal of better understanding doctors' perceptions of VH

**Table 1**  
Doctor characteristics.

Pseudonym	Language Region (German or French)	Type of Doctor	Number of Consultations Observed	Years Practicing Medicine	Location of Practice	Sex
Dr. Rüesch	German	General practitioner	4	17	Urban	Female
Dr. Oblinger	German	Pediatrician	2	20	Urban	Female
Dr. Amacher	German	General practitioner	1	43	Urban	Male
Dr. Balen	German	Pediatrician	0	10	Urban	Female
Dr. Gersbach	German	Gynecologist	0	26	Suburban	Female
Dr. Mattli	German	Pediatrician	2	31	Urban	Female
Dr. Topf	German	Pediatrician	0	13	Suburban	Male
Dr. Pieren	German	Family doctor	0	40	Rural	Male
Dr. Ammann	German	Gynecologist	0	15	Urban	Female
Dr. Caspari	French	Pediatrician	3	21	Suburban	Male
Dr. Dardel	German and French	Pediatrician	0	30	Urban	Male
Dr. Délèze	French	Pediatrician	4	10	Suburban	Female
Dr. Morand	French	Pediatrician	0	21	Rural	Female
Dr. Fischer	German and French	Pediatrician and school doctor	0	6	Urban	Male
Dr. Ferri	French	Gynecologist	0	15	Urban	Female
Dr. Meier	French	Gynecologist	0	27	Urban	Female
Dr. Rossi	French	General internist and infectious disease specialist	0	22	Urban	Male
Dr. Gilliard	French	Pediatrician and school doctor	0	25	Urban	Female
Dr. Chenuaux	French	Gynecologist	0	37	Urban	Female
Dr. Rossellat	French	General internist and infectious disease specialist	0	15	Urban	Female

N = 20

N = 16

and underimmunized patients, we ask the following questions: (1) how do doctors in Switzerland evaluate VH with their patients? (2) how do doctors describe their perceptions of patients based on their vaccination attitudes and behaviors? and (3) when seeing VH patients, how do doctors construct and manage their own roles, responsibilities, and reputations?

## 2. Methods

We conducted semi-structured qualitative interviews with biomedical doctors (N = 20) and ethnographic observations of vaccination consultations between doctors and parents (N = 16 consultations with 6 doctors from the sample of the interviewed doctors) between August 2017 and October 2018 in the French- and German-speaking regions of Switzerland (FR-CH and DE-CH, respectively). We first interviewed doctors and then observed some of their consultations in order to triangulate data from doctors' discourses through comparison to data collected from observations of what happened during consultations. We specifically focus on doctors because vaccinations consultations are usually conducted by physicians, predominantly pediatricians, and general internists in Switzerland.

We recruited doctors through our research networks by calling potential participants, sending recruitment letters and study flyers via email, and via snowball sampling. We purposively sampled vaccination consultations for observations in order to observe interactions with parents with whom doctors were likely to discuss vaccination for the first time or with parents considering their children's first vaccines.

MD, a sociologist trained in qualitative methods, conducted 10 interviews and observed 7 consultations in FR-CH. JN, a biomedical doctor with training in qualitative research, conducted 10 interviews and observed 5 consultations in DE-CH. PK, a senior medical student with training in qualitative methods observed 4 consultations in DE-CH.

Our transdisciplinary research team of medical sociologists, anthropologists, public health specialists, a pediatrician, and a general internal medicine and infectious disease specialist, along with the support of an advisory board of clinicians trained in biomedicine and CAM, a researcher in anthroposophic medicine, public health experts, and policy makers, collaboratively drafted a qualitative interview guide. The guide was based on VH literature and piloted for coherence and clarity prior to data collection. Questions were based on the

following themes: (1) doctors' background and training, (2) patient-provider interactions, and (3) perspectives on vaccination, immunity, and public health. Participants responded to open-ended questions in their own words. Interviews ranged from 34 to 82 min (average 63 min), were digitally audio-recorded, and transcribed verbatim.

Vaccination consultations were observed and documented in field journals. Following the consultations, we wrote field notes into a narrative format. We systematically filled out observation guides which were created with the research team, based on VH literature, and designed to capture items of interest; we documented the reason(s) for consultations, the person who initiated vaccination discussions, the vaccinations discussed, the amount of time spent discussing vaccines, and our interpretations of doctor and parent emotions and communication styles.

MD and AB analyzed the interview transcripts and consultation observation narrative accounts in the original language of utterance, and analyses were complemented by regular discussions with the main research team. We made a point to reflexively discuss our own perspectives during analysis in order to minimize the bias potentially introduced by our own beliefs, experiences, and assumptions. Research discussions were guided by the Framework Method (Gale et al., 2013) which provided structure to our analysis based in constructivist grounded theory (Charmaz, 2006). In other words, through several in-depth readings of the data, we iteratively revisited our analytical framework by inductively coding segments of text into themes which emerged from the data. Throughout data analysis, we used sensitizing concepts (Bowen, 2006) so as to retain our focus on patient-doctor interactions, doctors' perceptions of patients based upon their vaccination perspectives, and influences on doctors' vaccination perceptions. Data were coded, and our analytical framework was revised with the support of MAXQDA software (VERBI, 2018).

The local ethics committee (*Ethikkommission Nordwest-und Zentralschweiz*) approved the conduct of the study. We obtained informed consent from participating doctors for interviews and both parents and doctors for observations. Quotes from interviews or observations have been translated into English. Pseudonyms are used for all participants.

### 3. Results

After thematically analyzing the data collected from interviews and observations, we organized our findings in line with the study research questions. Participant characteristics can be found in Table 1. We first describe how doctors' discourses depicted different types of patients based upon patient vaccination attitudes and behaviors. We then discuss the various dilemmas participating doctors face when seeing VH and underimmunized patients. We finish the results section by showing how such dilemmas raised questions related to doctors' professional reputations and legitimacy, not only among patients, but also with other HCPs.

#### 3.1. Testing the waters and diagnosing levels of hesitancy: different types of patients

An essential first step when discussing vaccinations with patients involved doctors *testing the waters* to gauge to what extent patients express VH. Evidence from interviews and observations show how, in such encounters, doctors assessed and diagnosed VH similarly to how clinicians diagnose medical conditions. However, instead of focusing on physical conditions, they diagnosed levels of VH. Through this process, doctors constructed different types of patients and tailored communication accordingly.

Doctors described the initiation of vaccination discussions with new patients as short, sometimes apprehensive, consultation moments. Dr. Ferri described such instances, "There is always a brief moment where I say to myself, 'How is this going to go?'"

Doctors' descriptions of initial encounters detailed how they were quickly able to discern levels of VH through communication, affect, and feeling. They explained how they could "see quickly," "feel right away how patients react," and "sense that people are a little hesitant." Dr. Délèze explained how patients convey VH, "They start off by telling me that they're not really into medicine. As long as they can do something homeopathically, they will. Or that they have not been vaccinated themselves." Dr. Topf described his experiences, "You realize [their perspectives] very quickly in the consultation. Even before I start talking about vaccines, you sense people a little bit. Then, I already have the impression, 'Yes, this is going to be difficult.'"

Doctors' discourses constructed different types of patients which do not fit neatly into previously discussed 'good' and 'bad' patient archetypes. Doctors' descriptions retained the common "for or against" narrative in vaccination discourses, but only to a certain extent. Doctors used the terms "pro" and "anti" vaccine in their discussions, but their explanations provided nuanced descriptions of patients' vaccination attitudes. Dr. Pieren's comments reflect this, "I would say about 80% have no questions. (...) Around 5% say, 'We decided against vaccination.' (...) About 10–15% have further questions about one vaccine but are not against it." Overall, doctors' discourses placed patients into three main categories: (1) compliers, (2) hesitant, undecided, or skeptical patients, and (3) refusers or non-vaccinators.

**Compliers.** Compliers follow providers' recommendations and trust doctors and their advice. Most patients fell into this category. Dr. Dardel explained how patients actively sought out vaccinations, "A lot of people come especially for the vaccines. They are surprised if there is a consultation without vaccines. (...) Especially immigrants. For them, it's normal to vaccinate." Since our discussions with doctors focused on vaccine hesitant and underimmunizing parents, the doctors did not describe compliers in great detail. Compliers adhered to normative vaccination practices, and doctors did not often elaborate upon these parents' motives for vaccination.

**Hesitant, undecided, or skeptical patients.** These patients were the most heterogeneous group. In terms of their backgrounds, doctors found it difficult to ascribe them specific characteristics as a rule but generally noted these individuals as having attained higher education, from the upper-middle class, and health conscious. Doctors described a

subgroup of patients who vaccinate despite concerns, a subgroup Enkel et al. (2018) refer to as 'hesitant compliers' in their analysis. Participants explained how some hesitant patients had specific questions that could be answered quickly or by providing fact sheets. Others required more of the doctors' time and wished to engage in detailed discussions. These types of patients had concerns about necessity, safety, novelty, and age appropriateness of certain vaccines.

**Refusers and non-vaccinators.** Doctors rarely had vaccine refusers and non-vaccinators in their offices. Many nonetheless described them as a source of tension and frustration, using a range of rather negatively connoted vocabulary to describe them. Participants described refusers as "alternative," "selfish," being from "hardcore, mega anti-vaccination regimes," "stubborn," "determined," "dogmatic," "informed," and as people whose "minds were made up." Dr. Rossi expressed concern that anti-vaccine individuals were collectively "gaining ground" and "a little bit like the Taliban" in their extremism. Several doctors reported how engaging in dialogue with refusers often proved to not be worth their time or energy because they perceived these patients' stances to be immutable.

#### 3.2. Dilemmas in addressing vaccine hesitancy

Although participants reported a minority of their patients falling into the latter two categories, virtually all doctors described how consultations with hesitant patients occupied more of their time. These patients proved to be more challenging, required more emotional capacity, and confronted doctors with more dilemmas than their interactions with compliers.

That said, some doctors lauded patients for having skeptical stances. For instance, Dr. Ammann explained, "[Adolescents] are allowed to think about [the HPV vaccine]. I give them a brochure (...). I let them ask critical questions." Dr. Caspari expressed a similar idea, "These are people who ask questions. It's not a complete refusal of vaccines. Generally, skepticism is a sign of intelligence. (...) It all depends to what degree there is skepticism, I suppose."

Dr. Oblinger realized she had overestimated how many hesitant patients she had in her office, explaining, "It was funny. I always said, 50% [of parents] are vaccine hesitant. Then I realized when I did a survey that my subjective perception was completely wrong. About 5% of my patients are vaccine hesitant." Such a realization echoes Dr. Caspari's assertion that these patients may be perceived as "problem patients," and shows how doctors may overestimate their prevalence. Not all participants would likely agree that such patients are problems. However, it was clear from the interviews and observations that their interactions with VH patients put them into memorable situations bringing them to reflect about their responsibilities *vis-à-vis* vaccination. Below, we describe some of these dilemmas, which lays the groundwork for discussion around what they reflect not only about patients themselves, but also about how relationships with VH patients has repercussions for the construction of doctors' professional responsibilities, identities, and reputations among patients and HCPs.

##### 3.2.1. Accepting non-vaccinating patients

Reflecting one of the preoccupations of public health literature, participants discussed refusing to treat non-vaccinating patients. Whereas no interviewees reported actively refusing underimmunized patients, several were aware of colleagues, particularly pediatricians, who categorically refused them. Dr. Delèze, who had opened her practice several years before the interview, described how she had begun establishing a patient base by accepting hesitant and non-vaccinating patients. She began facing difficulties in continuing their care, "It's starting to weigh on me to have a lot of non-vaccinated patients. The day that I have a child who catches measles in my waiting room, I'll have trouble sleeping." Such reflections brought her to clarify the dilemma in which she found herself:

"I'm not really sure where to position myself. Should I just refuse [unvaccinated patients] as a principle? But that means that I would show the door to quite a few families. (...) Vaccination specialists don't recommend that we do that because they say that this creates whole casts of unvaccinated children. (...) I just think about how I completely disagree [with some parents] on this principle and how I won't be able to give them proper care."

Concerned with the potential of measles outbreaks occurring in her private practice, Dr. Délèze explains her conflicted position by weighing her own personal feelings on the matter against biomedical recommendations from "vaccination specialists."

Several doctors were conflicted due to previous clinical encounters with vaccine preventable diseases resulting in severe health consequences or death. They struggled coming to terms emotionally with these experiences and hoped to prevent similar situations. Dr. Gilliard remembered a baby contracting measles from exposure to an unvaccinated individual, "I saw a 3-week-old baby die from measles and find it unacceptable that this can happen nowadays (...) even though there is an excellent vaccine. This shouldn't happen." In other testimonies, doctors similarly questioned why these preventable diseases and deaths could occur when they could be prevented with vaccinations. Many felt a responsibility to continue providing care to non-vaccinating individuals in the hope that they might change their minds.

### 3.2.2. Individualization and delays

Doctors expressed somewhat negative attitudes and ambivalence about modifying the recommended vaccination schedule. Dr. Fischer described how recommendations were already "complicated enough," elaborating, "In order to avoid errors, we need standardization." When asked about *à la carte* schedules, Dr. Morand called them a "tedious" nuisance, explaining, "It's hours spent on discussion. We try to stay calm and say, 'Listen, let's talk about each disease, one-by-one. So, why do you want to protect [your child] against tetanus but not meningitis?'"

Other doctors echoed Dr. Morand's efforts to remain calm, citing the importance of informing patients about each vaccine, even in cases of disagreement. Dr. Gilliard explained, "I think these people understand that I disagree. (...) But what is the most important for me is that these babies and children receive medical care." Dr. Rossi expressed being personally against delaying vaccinations but explained sometimes needing to find a compromise, "For anti-vaccine parents, if they are only partially convinced and they accept to vaccinate a little later (...), I think that it's the lesser of two evils than those who refuse everything."

Others did not take issue with patients requesting individualized vaccination, particularly for premature or ill infants. For instance, Dr. Rüesch explained how some mothers, most from Switzerland and some from eastern Europe, prefer delaying vaccinations, "If the child doesn't attend daycare and if there are no other specific reasons, I don't force anyone to vaccinate. (...) [Some parents] don't want to vaccinate against everything. They want to wait a bit. They simply want a differentiated vaccination schedule. We can do that. I don't really care." In these cases, doctors reported a tendency to prioritize certain vaccines, such as MMR (mumps, measles, rubella), tetanus, and pertussis. Doctors expressing willingness to diverge from Swiss recommendations explained how they insisted less on certain vaccines, such as those classified as complementary vaccines by the FOPH. Some pediatricians reported being conflicted when offering HPV vaccinations to younger patients, such as those 11–13 years old, citing the challenges in broaching sexuality with adolescents. In these instances, doctors felt that these discussions were the responsibility of schools or parents and preferred that the decisions were made outside of their offices.

### 3.2.3. Maintaining dialogue and trust

When counseling VH patients, doctors commonly discussed the necessity of engaging in meaningful and careful dialogue. When describing initial discussions, Dr. Délèze explained how she evaluated

potential for communication, "If the parents are against [vaccination], I try to measure to what extent they are against it to see if it's a subject that we can or cannot talk about." Dr. Rossi also discussed the prerequisite of an exchange, "I can take more time as long as I feel there is a discussion. From the moment when I feel that we have finished the discussion, there are no more arguments or exchanges of different viewpoints, or we are overemotional or dogmatic, I stop there." Furthermore, Dr. Oblinger described how her approaches had changed over the years:

"In the past, I would bring up arguments and become emotional myself. Now, I realize that if I speak more neutrally, [parents] come back. But you can't always give the same answer. You have to get a feel for where the parents are. (...) You can't put on a pre-recorded tape."

In all of these instances, doctors recognized the importance of individualizing the vaccination discussions in order to tailor them according to patients' willingness, or lack thereof, to have productive conversations about vaccination.

A common compromise doctors made during difficult consultations involved them insisting less or avoiding discussions with parents they perceived as determined to not vaccinate. Dr. Dardel expressed concern that too much insistence might result in trust being "broken" with parents. Dr. Rossellat explained how these consultations were "difficult" and described these instances as being filled with "tension." She elaborated, "I've never had a person like that change their mind. Actually, it's difficult to know what I should do because I just create more tension. For me, it's extremely important to inform them." Dr. Rüesch justified ending such vaccination consultations due to time constraints, "I don't argue anymore with those who ideologically think that vaccinating causes harm because my time is too precious, honestly." When counseling those who were decided not to vaccinate, it was common for doctors to describe disengaging from discussion in order to mitigate the perceived potential for conflict and to save time.

### 3.2.4. Patients planting seeds of doubt into doctors' knowledge

When we asked how to improve vaccination communication, many doctors reported a desire to feel more supported in "knowing the facts" in order to be more informative in consultations. Doctors argued that higher confidence in their own knowledge could improve communication with VH patients. Dr. Meier discussed a desire to be comforted by the scientific literature and explained, "Patients put doubt into what you know. (...) Scientists and researchers don't do enough to try and to put at ease some of the worries."

Several doctors also wanted to further understand patients' information sources and anti-vaccination arguments. Dr. Rossellat recounted the difficulties of having patients who come to appointments "armed" with anti-vaccination arguments, "The worst is when they have seen a television report or something that is super up-to-date. Then they come with these arguments, and I haven't seen what they have." Dr. Gersbach noted how patients "all go and ask 'Dr. Google.'" Such statements reaffirm the idea of VH individuals as active agents, both in medical encounters and in health information seeking behaviors.

### 3.3. Professional reputations, vaccine hesitancy, and underimmunization

Doctors positioned their vaccination views and practices by referring to official recommendations and medical literature, responsibility toward their patients and society. They also referred to their reputations among patients and colleagues. Many framed their practices by distancing themselves from VH and anti-vaccine HCPs. The evidence we gathered overall constructed normative discourse surrounding acceptable ways to address VH as HCPs by actively pursuing vaccine uptake, despite the dilemmas described above for which there were no straightforward solutions.

An underlying theme to the construction of doctors' reputations around vaccination involved the figure of 'good' and 'bad' doctors and HCPs. Similar to the 'good'/'bad' patient distinction, our goal is not to ascribe doctors into such categories but rather to call attention to how doctors perceived themselves and their colleagues in similar terms. Additionally, our evidence shows how doctors were aware of vaccination-related reputations, both about themselves and about other colleagues, and how they could easily spread among patients and colleagues.

### 3.3.1. Managing reputations with patients and positioning professional practices

Doctors explained how they felt they were perceived by VH and non-vaccinating patients when promoting vaccinations. Several described such patients' perceptions of them as "corrupt" and "in the pockets of pharmaceutical companies." Dr. Rossellat recounted, "[Patients] always have the impression that you are on the side of public health and pharmaceutical lobbies. You're kind of perceived as the bad guy." Such statements echo Lupton (1996, 1997b)'s findings showing how doctors and patients alike perceived 'bad' doctors as being corrupt and having purely financial interests.

Several doctors reported clearly stating their vaccination positions in order to avoid ambiguity with patients. During a consultation with a mother and father of a 5-week-old, we observed Dr. Mattli respond to the mother's request for vaccination counseling. After describing the FOPH recommendations, Dr. Mattli explained her position by distancing herself from headline vaccination advocates and opponents. We here recount this episode from observation notes:

Dr. Mattli mentioned there were anti-vaccine people, explaining that in her view, both sides used fear to influence others. She clarified that she was "no vaccination Taliban" and that she did not use fear with patients. She told the parents, "No matter what you decide, I'm going to care for you." She concluded by repeating her recommendation to follow the official vaccination schedule.

Some doctors explained a need to distance themselves from their perceptions of CAM providers' vaccination practices and beliefs. Dr. Délèze, for example, discussed a reputation she had begun having among patients due to her acceptance of unvaccinated patients, "People come for that reason and say, 'Yes, you're open [to non-vaccination].'" I correct them quite often. I say that I am not a homeopath, that I am pro-vaccine, and that I do not want any confusion about my title. Unfortunately, it's a reputation that can spread more quickly than others." We observed such professional distancing during a consultation with Dr. Délèze and a mother:

Dr. Délèze asked if they were going to continue the vaccination schedule they had previously agreed upon. The mother hesitated before saying that she had been wondering about aluminum in vaccinations. She appeared embarrassed in divulging that she had seen a homeopathic doctor who had brought up the topic. Dr. Délèze, frowning, seemed annoyed about having to address this issue. She slowly explained that the homeopath was correct about aluminum being in some vaccines in small amounts in order to prompt an immune reaction. Dr. Délèze then asked the mother if the other doctor had changed the mother's mind. The mother slowly mumbled that he had not, she was "100% for vaccines," and explained how the homeopathic doctor had introduced doubt into her mind. Dr. Délèze shook her head disapprovingly and said, "They're good at doing that."

In Switzerland, where CAM use is popular, Dr. Délèze found it important to assert biomedicine's legitimacy in opposition to CAM, which she associated with doubt about vaccines and anti-vaccine attitudes. Other participants also commonly associated VH and vaccine refusal with CAM. Dr. Dardel recounted why he saw relatively few VH patients, "People who absolutely don't want to vaccinate maybe go see a different type of doctor. (...) A large majority of my patients are convinced

of the importance of vaccinations. (...) The others see homeopaths or people who practice natural medicine."

Overall, doctors reflected about how they positioned themselves in terms of their level of support for vaccinations with their patients and what this meant for how patients perceived them. Sometimes, this meant presenting themselves to patients as providing emotionally "neutral" approaches, as Dr. Mattli explained to the parents in her consultation. For others, this meant differentiating their practices and recommendations from the recurring figure of the anti-vaccine CAM provider.

### 3.3.2. The intraprofessional gaze

During interviews, doctors compared their vaccination practices and perspectives to those of their colleagues and to official recommendations. As evidenced by the introductory quote from Dr. Caspari, accepting anti-vaccine patients was at one point in his career viewed as a "failure of the pediatrician." He explained how when he was a pediatric intern, doctors who vaccinated less were "pointed at by other doctors," and called "blue flowers," with the suspicion that they "practiced homeopathy." Having felt this normative expectation from his colleagues about vaccination, Dr. Caspari wondered if his acceptance of VH patients brought judgement from colleagues. He nonetheless expressed relief in knowing that he had expert support, "Luckily, I had the support of vaccinologists to help me to know that I'm right [to accept these patients]."

Participants reported being aware of normative expectations from colleagues, Swiss recommendations, and medical literature to promote pro-vaccination discourse and increase vaccination uptake. They also reproduced similar discourse during interviews by discussing other HCPs' vaccination practices. Some commented on HCPs' vaccine doubts and questioned where they came from. Dr. Ferri expressed her astonishment about VH doctors, "Part of the problem is that there are people from the medical field who claim to be medical but are skeptical towards vaccination. That can be quite destabilizing for people." She then wondered, "How can a doctor with the same training as me be so opposed to vaccination?"

Several doctors criticized other HCPs' decisions to dismiss families who refused vaccination by pointing out the ethical considerations, epidemiological consequences, and doctors' responsibilities in providing care to everyone. Dr. Oblinger described a difference of opinion that she had had with a colleague in her shared practice. Her colleague wished to dismiss parents who did minimal vaccinations. Dr. Oblinger explained to her, "My mission as a doctor is to accompany everyone, especially those who have doubts." She elaborated, "It's bad that a pediatrician (...) might select [patients] or refuse them. (...) In doctors' offices in the Netherlands, everyone goes, and the doctors have to take them. (...) Here, you can say, "I just take German-speaking Swiss residents who are willing to vaccinate."

Doctors commonly perceived CAM practitioners as perpetuating anti-vaccine discourse. Dr. Rossi explained, "Often, there has already been a discussion with an alternative doctor, who played the role of pediatrician or general practitioner and who has already convinced the parents." Other doctors expressed concern about other HCPs' training and information sources. Some discussed how midwives or nurses might be spreading information that encourage people to vaccinate less and suggested regular refresher courses as a possible remedy. Dr. Balen explained how there should be stricter surveillance for HCPs regarding the information they provide to patients, "We currently can't forbid [HCPs] from making divergent recommendations. I think we should actually be obligated to inform parents according to the latest scientific standards." In other words, participants hypothesized that certain HCPs were at fault in promoting negative vaccine attitudes. Others, through discussion of other HCPs' questionable practices, such as dismissing patients for their vaccination perspectives or decisions, implied that there were unacceptable ways to address parents' VH.

#### 4. Discussion

Evidence from our observations and interviews shows how doctors screen, diagnose, and measure patients' levels of VH. Doctors' classifications of patients based upon their vaccine perspectives set the stage for different styles of communication with different types of patients. Although the categories they constructed are similar to other typologies in VH literature (Leask et al., 2012; Rossen et al., 2019), doctors' subjective descriptions of different types of patients have not yet received much research attention. Furthermore, analysis of participants' perceptions of how other HCPs address VH provides important insight into medico-professional expectations about addressing VH in practice.

Framing patients and doctors into 'good'/'bad' binaries is admittedly limiting but nonetheless conceptually useful. This heuristic exercise brings to the fore the shifting roles of patients and doctors in contemporary societies, where the abundance of health information circulates via mass media and online more quickly than ever before (Dedding et al., 2011). VH therefore serves as an emblematic case study of challenges doctors encounter in interactions with well-informed or uncertain patients, with such challenges underscoring the often-overlooked paradoxes of addressing VH in clinical practice.

One paradox results from recent sociomedical trends shaping 'good' patients and healthcare consumers as inquisitive, autonomous, informed individuals who are active participants in health decision-making (Armstrong, 2014). Research shows that these characteristics generally ring true for VH individuals (Reich, 2018). However, by questioning biomedical knowledge in an attempt at being 'good' patients and potentially not adhering to vaccination recommendations, VH parents cross the lines into 'bad' patient territory. This paradox is particularly useful for researchers and clinicians because it aids in understanding VH individuals' rationales from a patient perspective instead of labelling patients with vaccination questions as categorically anti-vaccine. This paradox also calls attention to how, as other research has shown, parents who actively seek out information are doing so in the best interests of their children (Wang et al., 2015). Researchers and clinicians will benefit from understanding that criticizing information-seeking parents and VH individuals serves as a punishment for such behaviors, which have been encouraged by health promotion efforts over the last several decades.

Another paradox results from the consideration of what constitutes 'good' and 'bad' doctors. As discussed above, 'good' doctors are meant to be good communicators, empathetic, and involve patients in the decision-making process. They are also expected to elicit patient adherence to public health vaccine recommendations. When patients do not adhere, doctors risk becoming 'bad' doctors in the eyes of the medical establishment. Faced with potential loss of face, doctors are, in the 'good/bad' binary model, expected to maintain communication, show empathy, and involve patients in decisions which transgress official vaccination recommendations. This paradox demonstrates how doctors are situated in a network of conflicting expectations in which they are called upon to situate themselves and their professional practices. Moreover, this paradox is particularly salient because it calls attention to the tensions involved when translating 'one-size-fits-all' approaches to individually meaningful approaches in clinical practice. In effect, as the evidence we gathered shows, participants reported the necessity of adopting pluralistic approaches in order to tailor communication according to patients' vaccination attitudes and practices.

A common construction in participants' discourses around VH patients was the figure of the 'problem' patient. Such patients required more of the doctors' time, communication skills, and medical expertise due to their additional questions, diverging viewpoints from biomedicine, and questioning of the legitimacy of health systems and doctors' expertise. However, not all participants' accounts fully support the caricatured image of these patients as "problems." Despite the challenges they posed, some doctors described such skepticism as a healthy, and even scientific, stance for patients to take. As long as dialogue was

possible, most participants were open to patients' vaccination questions and understanding of their reluctance to vaccinate. This finding brings a more nuanced picture of patient adherence and 'good'/'bad' patients to the sociological literature and underscores the problematic nature of persisting 'anti/pro' dichotomies in vaccination discourses (Brunson and Sobó, 2017).

One of our most striking findings demonstrates how doctors' self-perceived professional responsibilities and reputations were linked to how they addressed VH. Doctors were aware of having certain reputations among patients *vis-à-vis* their openness to VH or non-vaccination. These reputations circulated among networks of hesitant patients who actively sought doctors empathetic toward VH patients. Participants also discussed how the spread of these reputations could reinforce their own positions, which manifested through doctors encouraging patients to adhere to vaccination recommendations. Additionally, their discussions of these reputations constructed HCPs who deviate from official vaccination recommendations, or who support patients' VH, as practitioners who fail to meet their professional responsibilities.

Some doctors problematized their reputations among colleagues and patients by insisting that they did not want to be known as non-vaccinating doctors or to be associated with CAM. Findings from Deml et al. (2019b), however, suggest that CAM providers in Switzerland are not categorically opposed to vaccination. Participants' perceptions associating CAM and non-vaccination likely reflect diverging epistemologies between biomedicine and CAM. That said, this interprofessional distancing may have been exaggerated by study participants due to our focus on vaccination. For example, a representative study, unrelated to vaccination, of pediatricians in Switzerland reported that 23% of respondents had attended complementary medicine (CM) training, 65% were interested in pursuing CM training, 16% provided CM to their patients, and more than 50% used CM for themselves or their families (Huber et al., 2019).

#### 5. Conclusions

Professional reputations being intertwined with how doctors address VH and underimmunization clearly has implications for patient-HCP interactions. Future research could benefit from heightened attention to the roles and expectations that HCPs have internalized regarding vaccination. Our findings bolster Karafillakis and Larson (2018)'s assertion that researchers should focus on issues facing HCPs: "The burden of addressing public and parent hesitancy cannot be placed on health professionals, without first taking the time to understand and address their own concerns and to build their confidence" (p. 800). Likewise, future research will benefit from paying attention to the affect and feelings that HCPs associate with such clinical encounters. As we have shown, doctors are not immune to emotions in their experiences with vaccination consultations. Additionally, doctors regularly engage with parents who value the emotional aspects of clinical encounters and who have expectations of being listened to and taken seriously.

Our findings raise an important question for vaccination consultations: is the more important goal to achieve vaccination uptake or to better inform and communicate with VH patients about the consequences and benefits of their choices? Insisting too heavily on vaccination uptake, without actively engaging with patients' hesitancy, can lead to the stigmatization of hesitant and non-vaccinated individuals. Approaches focusing primarily on adherence likely undermine public health goals of increased vaccination uptake because pro-vaccination communication can be perceived as condescending, belittling, or patronizing to those who hesitate or actively choose not to vaccinate (Nyhan et al., 2014; Masaryk and Hatoková, 2016). When patients feel belittled or patronized, other determinants of vaccine acceptance suffer through the erosion of trust in HCPs, public health institutions, and biomedicine. The philosophical and ethical analysis of the doctor-

parent relationship provided by Navin (2015) shows how the clinical encounter provides opportunities for doctors to gain, maintain, or lose patient trust in biomedicine. He explains, “when a pediatrician refuses to respectfully respond to a mother's worries about the necessity or safety of vaccination, (...) he may also undermine the trust she is willing to place in his testimony about vaccines (p. 30, emphasis in original).

VH and underimmunization are complex, multifaceted social phenomena, and HCPs play substantial roles in shaping patient perceptions around vaccination and vaccine uptake. It is therefore important to be attentive to the expectations created for HCPs by dominant public discourses around vaccination and the growing body of scientific literature's recommendations about addressing VH in clinical practice. Doctors' internalization of this oft-polarized social issue and of the intraprofessional medical gaze, which promulgates normative vaccination practices, may increase doctors' apprehension about engaging with vaccine hesitancy and underimmunization due to anxieties of “failing” their patients, the public, and their profession.

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### Appendix A. Supplementary data

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## Chapter 5

# "I don't want my stomach in knots every time I see my son's doctor!": Parental trust, affect, and choice in vaccination decision-making at the nexus of complementary and alternative medicine (CAM) and biomedicine

### Notes

This chapter is an unpublished working paper.

### Abstract

Complementary and alternative medicine (CAM) is used by 25-50% of the Swiss population and is integrated into the Swiss healthcare system when offered by biomedically trained medical doctors with postgraduate training in certain CAM approaches. Previous research has associated CAM use to unfavorable attitudes or rejection of vaccination. This article therefore seeks to understand the interplay between biomedicine and CAM in vaccine hesitant and vaccine rejecting parents' different logics of healthcare related to their vaccination decisions. With the support of qualitative evidence gathered from in-depth, semi-structured parental interviews (N=30) and from ethnographic observations of vaccination consultations between parents and doctors (N=18 consultations with 5 CAM doctors; N=16 consultations with 6 biomedical doctors), we explicate parents' rationales about their healthcare decisions *vis-à-vis* vaccination from their own perspectives. Such rationales include vaccine skeptical parents' adherences to 'natural,' 'chemical free,' and anti-Western medicine regimes of healthcare, perceptions about controlling exposure to infectious diseases and risk mitigation, and desires for individualized vaccination counseling. We then analyze parental vaccination decision-making at the nexus of CAM and biomedicine by showing that there is not always a clear-cut, direct relationship between (non)vaccination and parents' use of CAM and/or biomedicine. With the conceptual support of Albert O. Hirschman's (1970) *Exit, Voice, and Loyalty*, we describe how parents navigated the selection of their children's healthcare professionals (HCPs) by framing these decisions in terms of trust, affect, and choice. Our findings add to vaccine decision-making literature by further demonstrating the importance of understanding parents' contexts and logics in vaccination consultation settings. Our results suggest that HCPs could benefit both from an increased understanding of these logics and from an increased awareness around the importance parents attribute to affect in clinical encounters.

# 1 Introduction

Between 25 and 50% of the Swiss population uses complementary and alternative medicine (CAM) and show favorable CAM attitudes (Wolf et al., 2006; Simões-Wüst et al., 2014; Klein et al., 2015). Research has associated parental consultations with CAM practitioners to negative vaccination attitudes and/or lower vaccination uptake than among parents who do not consult CAM providers (Zuzak, 2008; Wardle et al., 2016). However, such studies have not been able to establish causality in these associations.

Despite the popularity of CAM use and the absence of vaccine mandates in routine settings in Switzerland (Masserey Spicher, 2010), childhood vaccination rates remain overall high (i.e. 87-93% nationally for 2 doses of mumps, measles, and rubella vaccine for 2-, 8-, and 16-year-olds). Depending on the vaccine, these rates have remained relatively stable or slightly increased over the past 20 years (FOPH, 2018a).

Setting it apart from most other high-income Western countries, providers of CAM in Switzerland are often biomedically trained medical doctors with additional CAM training (Hart, 2017). There is generally equitable access to medical services provided by CAM and biomedical doctors since the Swiss voted in 2009 to integrate CAM into the healthcare system by including its reimbursement through basic mandatory health insurance (Saller, 2009; Debons, 2015). As a result, CAM services are covered by basic mandatory health insurance when provided by medical doctors with additional postgraduate training in anthroposophical medicine, Traditional Chinese Medicine (TCM)/acupuncture, homeopathy, or phytotherapy (FOPH, 2018b). In Switzerland, there is a higher probability of CAM being used among individuals with chronic illness or self-reported poor health, women, middle-aged people, and more highly educated individuals (Simões-Wüst et al., 2014; Klein et al., 2015).

Switzerland provides an excellent setting to study the relationships between biomedicine, CAM, and parental vaccination decision-making in a supposed free market of healthcare. This article ties three complementary strands of literature together with the aim of providing more insight into parents' navigation of vaccination decision-making in their interactions with, and selection of, practitioners of biomedicine and CAM. The first strand of literature finds support from research demonstrating the ways vaccine hesitant and rejecting parents conceive of varying "logics of care" (Ward et al., 2017). The second strand of literature deals with the recognition of the important roles played by healthcare professionals (HCPs), particularly doctors, and institutions in influencing parental perceptions of vaccination and vaccination behaviors (Benin et al., 2006; Opel et al., 2013; Paterson et al., 2016; WHO, 2019). The third strand of literature borrows from Hirschman (1970)'s seminal text for organizational theory wherein he develops the concepts of *exit*, *voice*, and *loyalty*.

## 1.1 Logics of care among vaccine hesitant and rejecting parents

Research has shown that parents' vaccination decision-making is not a standalone issue that can be considered outside of parents' social contexts (Larson et al., 2014; MacDonald, 2015; Bedford et al., 2018). Vaccination decisions are tied into more complex issues related to gendered parenting (particularly mothering), personal histories, birth experiences, perceptions of control and exposure to disease, perceptions of responsibility for children's health and development, vaccination norms among parents' social networks, and risk perceptions of (non)vaccination (Poltorak et al., 2005). Common parental concerns about vaccination are related to vaccination's efficacy, necessity, timeliness, and perceptions around vaccine side effects or about the probability of their children contracting vaccine preventable diseases (VPDs) (Dubé et al., 2013; MacDonald, 2015).

Researchers' discussions around vaccination decision-making, particularly vaccine hesitancy and refusal, point to the Western ideals of *intensive mothering* (Hays, 1996), characterized by investment of upper-middle class women's time, energy, money, and social resources in the pursuit of obtaining the social status of *good mothers* through the continued management and mitigation of risk and health promoting activities for children (Lupton, 2011; Reich, 2014; Sobo, 2015, 2016). Several studies have argued that vigilant parenting practices exemplify a 'do-it-yourself' approach, which brings parents to see themselves as experts about their children and that their decisions bring them to be ultimately responsible for their children's well-being (Reich, 2014; Navin, 2015; Reich,

2016a). Such logics are expressed by parents' continued engagement with the rhetoric of *choice*, which scholars have argued being tied to neoliberal ideals favoring ideals of freedom of autonomous subjects who view themselves as being able to exercise agency outside the confines of public health or governmental discourses related to personal decisions, such as vaccinating one's child (Reich, 2014; Ward et al., 2017).

Others have argued that vaccine refusal and hesitancy are associated with recent socio-medical movements (Peretti-Watel et al., 2015; Deml et al., 2019b), such as risk culture and 'healthism,' which is "characterized by high health awareness and expectations, information-seeking, self-reflection, high expectations, distrust of doctors and scientists, healthy and often 'alternative' lifestyle choices, and a tendency to explain illness in terms of folk models of invisible germ-like agents and malevolent science" (Greenhalgh & Wessely, 2004, p. 210). Parents' positions which adhere to healthism-type approaches have been shown to privilege 'chemical-free,' 'natural,' and 'immunity strengthening' parental practices in their vaccination decisions (Gross et al., 2015; Dubé et al., 2016; Reich, 2016b).

Furthermore, commonly held views among HCPs and practitioners of public health that vaccine refusing simply lack knowledge or information about vaccination have been called into question. Rather, it appears that vaccine accepting individuals generally have fewer correct vaccine-related beliefs than vaccine hesitant or rejecting individuals, and that the latter group seems to have informed themselves more extensively about vaccination (Benin et al., 2006; Leask et al., 2012; Dubé et al., 2013; Navin, 2015).

## 1.2 HCPs and institutions: Trust in biomedicine and CAM

A common theme in the literature on parental attitudes towards vaccination via their interactions with HCPs revolves around issues of trust. In general, parents who trust their children's HCPs are more likely to trust their vaccination recommendations (Benin et al., 2006; Ames et al., 2017). Research has pointed to the knowledge, attitudes, communication styles, information, and amount of time spent discussing vaccination during consultations with HCPs, doctors in particular, as important determinants of vaccination uptake and perceptions among parents (Bryant et al., 2009; Opel et al., 2013; Paterson et al., 2016).

Other research has shown that parents' (dis)trust in HCPs may be linked to the institutions they represent. For vaccine hesitant and rejecting parents, distrust of biomedicine and public health authorities is linked to the parents' perceptions of these institutions being tainted by the financial interests of doctors and hospitals and profit-seeking of the pharmaceutical industry (Salmon et al., 2015; Dubé et al., 2016; Attwell et al., 2018; Deml et al., In Revision). As Yaqub et al. (2014) point out, "the credibility of institutions seems to matter more than the information content itself" (p. 7) when it comes to parents' attitudes about vaccination. Furthermore, Lock and Nguyen (2010) argue that biomedicine is demarcated from other "medical traditions because of its systematic approach to objectifying, classifying, and quantifying the human body, itself assumed to be derived from a universal template" (p. 82). Such claims to universalistic approaches in medicine and public health, as vaccination has historically been framed, provide opportunities for dilemmas for biomedical practitioners seeking vaccination adherence with vaccine hesitant or rejecting parents who may prefer individualized approaches to healthcare (Deml et al., In Revision).

Research into CAM's relationship to parental vaccination attitudes and practices have recently begun sparking interest within vaccination decision-making literature (Dubé et al., 2016; Wardle et al., 2016; Attwell et al., 2018; Frawley et al., 2018; Deml et al., 2019b). Browne et al. (2015) link negative vaccination attitudes to individuals' preferences for CAM over conventional medicine, spiritual and intuitive ways of reasoning (as opposed to analytic, cognitive styles), and openness to new experiences. Studies unrelated to vaccination have shown that people may use CAM for various reasons, including satisfaction with the CAM encounter, understandings of the body and of health that different from biomedical ideologies, desires to combine both biomedicine and CAM, and dissatisfaction with biomedicine (Harris et al., 2012; Thomson et al., 2014; Leach et al., 2018).

Qualitative research has described elements of CAM provider encounters with parents that likely appeal to vaccine hesitant or rejecting parents' logics of care discussed above. For example, Pedersen (2013) demonstrated how 46 Danish CAM users commonly considered CAM as part of a 'risk-free' health regimen that 'could do no harm.' In a similar Danish study, Pedersen et al. (2016) describe how trust emerges in CAM clinical encounters through providers' active listening,

engagement with patients' bodies, and material experiences of the encounter, such as the way providers are dressed, the presence of potions, ointments, and decorations, or the use of music during consultations. Dubé et al. (2016)'s research with 56 mothers in Québec showed how, in the search of neutral, balanced information about vaccinations, "some vaccine-hesitant mothers considered that CAM practitioners were more credible than public health authorities because they had 'nothing to gain' by dismissing vaccination while governments were perceived as having a hidden agenda" (p. 416).

### 1.3 Exit, voice, and loyalty

Research has pointed to parents' transition from seeking healthcare services for their children from biomedical doctors to those of a provider of CAM, particularly around the issue of vaccination (Navin, 2015; Dubé et al., 2016; Deml et al., In Revision). We will here focus on this phenomenon by borrowing from the conceptual work of Hirschman (1970). In his classic organizational theory, political science, and economics text *Exit, Voice, and Loyalty*, Hirschman lays the groundwork to explain how individuals express (dis)satisfaction with the quality of products or services in free market contexts. He argues that customers have two options for expressing dissatisfaction with the quality of the product or service provided. The first option is "the exit option," (p. 4), by which customers discontinue purchasing the products or withdraw from the business relationship. The second option, "the voice option," (p.4) allows customers to "express their dissatisfaction directly to management or to some other authority to which management is subordinate or through general protest addressed to anyone who cares to listen" (*ibid*).

Hirschman advances that both of these mechanisms can be tied to economic and political action, with *exit* anonymously allowing individuals to invoke market forces to prevail without the nuisance of face-to-face confrontations. *Voice*, on the other hand, is "political action par excellence" insofar as "it implies articulation of one's critical opinions rather than a private, 'secret' vote in the anonymity of a supermarket" (p. 16). *Loyalty* to product or its provider is a mechanism which can either mitigate or promote individuals' propensity to enact the *exit* or *voice* option in cases of dissatisfaction. The argument also holds that when customers are satisfied with the quality of the service or product, loyalty retains customers' business.

We recognize that the consideration of parents making healthcare decisions for their children from a purely consumeristic approach has limitations. Lupton (1997), for example, provides critiques of consumeristic views of patients as purely rationale "dispassionate, thinking, calculating" subjects (p. 374). She convincingly argues in favor for consumeristic understandings of healthcare which are able to incorporate the desires, emotions, and needs that characterize the patient-doctor relationship. She explains how the emphasis people place upon the affective aspects of healthcare may lead patients to seek treatment from healthcare practitioners outside of biomedicine if they feel that their affective needs are not being met.

### 1.4 Research questions

The above discussions benefit our conceptual understandings of parents' choices in navigating the landscape of the Swiss healthcare system, characterized by the co-existence and relative ease of access of biomedicine and CAM for those enrolled in basic mandatory health insurance schemes. In our case, we are interested in parents' perceived quality of vaccination consultation services within the context of an assumed free market of healthcare options. This is particularly relevant, since researchers have shown how parents engage in a selection process for their children's healthcare practitioners in search of a provider that they can trust and with whom their values align, particularly in vaccination discussions (Navin, 2015; Dubé et al., 2016; Peretti-Watel et al., 2019). Peretti-Watel et al. (2019) describe this selection process with the metaphor of parents looking to find "a shoe that fits" (p. 1199).

We ask the following research questions: (1) how do vaccine hesitant or rejecting parents frame their use of CAM and biomedicine in relationship to different logics of parental care?; (2) how do parents position their vaccination attitudes and choices in relationship to CAM and biomedicine?; (3) to what extent do parents enact the mechanisms of *exit*, *voice*, and *loyalty* in their selection of biomedical or CAM providers for their children's healthcare, particularly for vaccination consultations?

## 2 Methods

This qualitative study is embedded within a larger national research program focused on vaccine decision-making for routine childhood vaccines and the HPV vaccine in Switzerland (Deml et al., 2019a). We collected data in the French- and German-speaking regions of Switzerland (FR-CH and GE-CH, respectively) between August 2017 and August 2018. We conducted semi-structured, qualitative interviews (N=30) with parents and ethnographically observed vaccination consultations between parents and practitioners of CAM and biomedicine (N=34). The parents we observed during consultations were not the parents we interviewed.

We sent recruitment materials (flyers and letters) to potential participants via our research team's various networks, via CAM and biomedical providers participating in the larger national study, and through snowball sampling with interviewed parents. Given the gendered nature of parental health decision-making for their children, a large majority of our parent sample was composed of mothers. We purposively sampled parents who reported CAM use than those who only consulted with biomedical practitioners. Our sample also purposively included more parents expressing vaccine hesitancy or rejection than vaccine acceptance. We organized the vaccination consultation observations with providers we had interviewed for the above-mentioned qualitative studies in order to observe consultations between providers during their first consultations with parents or during consultations where vaccinations were likely to be discussed for the first time.

Interviews with parents were audio-recorded and transcribed verbatim. The interviews were conducted based upon an interview guide that had been developed by the research team and which was rooted in relevant vaccine decision-making literature. The interview guide contained questions related to family backgrounds, parents' roles in health decisions, children's health and well-being, parents' use of CAM and biomedicine, parents' perspectives on vaccination and their decision-making process, and patient-provider interactions concerning vaccinations. We asked parents to provide copies of their children's vaccination certificates and discussed their vaccination status with the support of this document during interviews. The interview guide was piloted and revisited iteratively to improve the clarity and the flow of the order of the questions.

During vaccination consultation observations, we documented notes ethnographically in field journals. We subsequently wrote our ethnographic observations into narrative accounts in order to provide descriptions of what happened during the consultations. In a more structured approach, we systematically documented particular items of interest with an observation guide. The guide was based upon relevant vaccination decision-making and medical ethnography literature and prompted us to note the reason for the consultation, the person who initiated the vaccination discussion, which vaccinations were discussed, an estimate for how much time was spent discussing vaccinations, and researchers' interpretations of provider and parent emotions and communication styles.

The local ethics committee (Ethikkommission Nordwest- und Zentralschweiz) approved the conduct of the study. We obtained informed consent from parents for interviews and vaccination consultation observations. Quotes from interviews or observations have been translated into English. Pseudonyms are used for all participants.

We used the Framework Method (Gale et al., 2013) to guide our analyses of the interview transcripts and observations. Our analyses were also guided by constructivist grounded theory (Charmaz, 2006) in order to include themes which emerged from the data in order to understand participants' framings from their own perspectives. Throughout data analysis, we used sensitizing concepts (Bowen, 2006) in order to retain our focus on parental logics of care, vaccination perspectives, and parents' selection of practitioners of CAM and/or biomedicine *vis-à-vis* vaccination. We used MAXQDA software to code segments of text from the transcripts and narrative accounts of observations (VERBI, 2018).

## 3 Results

We interviewed a total of 30 parents (13 from FR-CH, 17 from GE-CH). Eight parents were interviewed as couples. We interviewed more mothers (N=24) than fathers (N=6). Most parents had attained education at a bachelor's degree level or higher. In 7 families, at least one child had received none of the recommended vaccines. In 11 families, children had been partially vaccinated or in a delayed fashion. In 8 families, the children had been vaccinated according to official

recommendations. Parents reported using CAM in 21 families. Table 1 provides further background characteristics, such as participants' employment type and rate of work.

We observed a total of 34 vaccination consultations (N=18 CAM consultations with 5 providers; N=16 biomedical consultations with 6 providers). The characteristics of observed providers are in Table 2.

We analyzed data and identified several themes related "logics of care," to borrow Ward et al. (2017)'s terminology, when it came to parents' health decision-making and health promotion activities. We have organized these logics of care relative to CAM and biomedicine, particularly as they relate to 'natural,' 'chemical-free,' approaches and stances critical of Western medications, parents' perceptions of the ability to mitigate risk, and parental preferences for individualized healthcare approaches. Second, we discuss how parents framed their vaccination decision-making *vis-à-vis* their use of CAM and biomedicine. Third, we demonstrate how parental perceptions of trust largely revolved around affect, social proximity, and choice in clinical encounters. These results lay the groundwork for a discussion of how these understandings can be understood with Hirschman's concepts of *exit*, *voice*, and *loyalty*.

**Table 1: Participant Characteristics**

Pseudonym	Age	Language Region (German or French)	Relationship Status	Number of Children	Employment Type and Percentage	Education	CAM Use
<b>At least one child has received none of the recommended vaccinations</b>							
Mrs. Crevoisier	48	French	Separated	4	Teacher; 100%	Bachelors	Yes
Mrs. Sandoz	35	French	Married	1	Social Worker; 10%	Bachelors	Yes
Mrs. Martin	37	French	Married	3	Physical Therapist; 40%	Bachelors	Yes
Ms. Besse	27	French	Single	1	Administrator; 50%	Vocational Training	Yes
Mrs. Heer	41	German	Married	2	Tailor, 100%	Vocational Training	Yes
Mrs. and Mr. Mayer	55, 54	German	Married	2	Daycare personnel, 100%; Illustrator, 100%	Federal Certificate	Yes
Mrs. and Mr. Schmied	Unavailable	German	Married	1	Nurse practitioner, 80%; Tradesman, 100%	Masters	No
<b>Children have been vaccinated partially or in a delayed fashion</b>							
Mrs. Galland	52	French	Separated	2	Medical Secretary; 70%	Vocational Training	No
Mrs. Chappuis	30	French	Married	2	Teacher; 70%	Masters	Yes
Mrs. Humbert	30	French	Married	2	Teacher; 70%	Masters	Yes
Mrs. Goff	30	French	Married	2	Homemaker	Bachelors	Yes
Mrs. Lopez	37	French	Married	2	CAM Practitioner; 100%	Bachelors	Yes
Mrs. Koch	43	German	Unavailable	4	Curative Teacher, 40%	Unavailable	Yes
Mrs. Bauer	35	German	Single, living with partner	1	Musician, 60%	Conservatory	Yes
Mr. Leo	47	German	Separated	4	Musician, no fixed rate	Conservatory	Yes
Mrs. Zurbrügg	45	German	Married	5	Lactation Consultant, Nursing Student, 100%	Enrolled in Bachelors	Yes
Mrs. Branknov	42	German	Married	4	Finance, 70%	Bachelors	Yes
Mrs. Kugler	37	German	Married	1	Social Education, 70%	Bachelors	Yes
<b>Children have been vaccinated according to official recommendations</b>							
Mrs. Godet	29	French	Married	1	Teacher; 70%	Masters	Yes
Mrs. Piccard	26	French	Married	1	Nurse; 80%	Bachelors	No
Mrs. Diesbach	32	French	Married	1	Teacher; 75%	Bachelors	Yes
Mrs. Bouvet	33	French	Married	4	Homemaker	Vocational training	Yes
Ms. Nowak and Mr. Büchi	37, 32	German	Not married, living together	1	Medical Doctors, 50%	Medical school	No
Mr. Müller	44	German	Married	1	Medical Doctor, 70%	Medical school	Yes
Mrs. Tanner	31	German	Married	3	Nursing Assistant, 30%	Vocational training	Yes
Mrs. and Mr. Hofer	34, 32	German	Unavailable	1	Fashion advisor, 50%; Unemployed	Vocational training	No

**Table 2: Characteristics of providers we observed**

Provider Pseudonym	Language Region (German or French)	Type of doctor and/or services provided	CAM or Biomedical Doctor	Number of Consultations Observed
Dr. Heffelfinger	German	Anthroposophic medicine	CAM	1
Dr. Welty	German	Anthroposophic medicine	CAM	5
Dr. Buchman	German	Traditional Chinese Medicine and Acupuncture	CAM	2
Dr. Schmidt	French	Anthroposophic medicine	CAM	5
Dr. Jansen	French	Homeopathic medicine	CAM	5
Dr. Rüesch	German	General practitioner	Biomedical	4
Dr. Oblinger	German	Pediatrician	Biomedical	2
Dr. Amacher	German	General practitioner	Biomedical	1
Dr. Mattli	German	Pediatrician	Biomedical	2
Dr. Caspari	French	Pediatrician	Biomedical	3
Dr. Délèze	French	Pediatrician	Biomedical	4
<b>N=11</b>				<b>N=34</b>

### 3.1 Vaccine hesitant and rejecting parents' logics of care

In participants' framings, the use of CAM and biomedicine was linked to their backgrounds and upbringings, health service use for themselves and of individuals in their social networks, and life experiences. Vaccine hesitant and rejecting parents commonly evoked their preferences for "natural" approaches to health and well-being, often arguing that it was important to avoid chemicals and unnecessary biomedical medicines. Parents frequently cited the importance of having options to mitigate potential risks associated with (non)vaccination, whether this be through limiting exposure to potential infectious Others in cases of non-vaccination or by reducing the perceived risks incurred by vaccinating. Finally, parents often framed their healthcare and vaccination choices at individual and family levels by arguing in favor of making the best decision for their own children.

#### 3.1.1 Natural, chemical-free, and medicine-free regimens

Many vaccine skeptical parents associated CAM with "natural approaches" and evoked the nefarious potentials of "chemicals" contained in biomedical medicine. Mrs. Godet, for example, explained, "Our family isn't pro-medicine. We won't necessarily go out of our way to give [our daughter] medicine." Many evoked the possibility of first resorting to CAM before seeking biomedical treatments. Mrs. Chappuis told us how her homeopathic pediatrician "always tries to treat by natural methods before giving medication. He would obviously give [our children] medication if they need it, but he will always try something else first."

Others noted the perceived limits of both CAM and biomedicine, with Mrs. Goff, whose father was a homeopathic general practitioner, explaining:

*Classical medicine takes general symptoms into account. Homeopathic medicine digs deeper. I mean that with general medicine, you can have 10 patients with a cold. They will all leave the doctor's office with the same medication. In homeopathy, 10 patients will leave with different doses and with 10 different medications. (...) Homeopathic medicine is very good, but there is no true [pause], there are no medications with either approach that can treat everything. There are flaws in both. There is no perfect medicine.*

Mrs. Godet reflected similar ideas while recognizing homeopathy's dependency on one's belief in its efficacy, "Well, homeopathy, you either believe in it or you don't."

Participants commonly described how they viewed CAM services to be complementary to biomedical approaches and noted how they might use them for different reasons. Mrs. Martin explained how she differentiated between the two approaches, "Traditional medicine is for health problems and child development. Complementary and alternative medicine is for things that are less important."

#### 3.1.2 Perceived mitigation of risk around (non)vaccination

For hesitant parents, many had considered the perceived risks incurred by vaccinating their children, such as uncertainty around adverse events or side effects, against the risk that their child contract a VPD. In both cases, parents reported different strategies they undertook in mitigating these perceived risks.

Some parents explained how their collective family lifestyles, such as 'healthy' eating, breastfeeding, physical activity, and avoidance of Western medicines (i.e. antibiotics), promoted the health and well-being of their children, thereby strengthening and reinforcing their children's immune systems.

Parents who chose not to vaccinate their children reported a host of strategies they enacted in order to avoid potential exposure to VPDs. Ms. Besse explained how she perceived limiting her son's exposures:

*I have many young mother friends with babies. If the babies are sick and we've planned to see each other, I'll cancel. If I need to go grocery shopping, I'll leave my son with my parents. (...) I really try to avoid public spaces with him. (...) I don't use public transportation either.*

Several parents referred to Switzerland as a "safe space," citing generally high vaccination rates, low rates of VPDs, and limited exposure to infectious Others as having played a role in their decision. Mrs. Crevoisier discussed how her decision to minimally vaccinate was inscribed into her family's life course, which had disrupted the love of travelling she had developed before becoming a mother. She explained, "I thought, 'What are the parameters of not vaccinating? Living in Switzerland, one. And two, no longer traveling because you decided not to vaccinate your children.'"

Some CAM providers reinforced the idea that parents could control exposure to VPDs by avoiding certain subgroups. In a narrative account of our observations, we note how Dr. Schmidt (FR-CH, anthroposophic medicine) explained this idea to a mother and father:

*The doctor explained that, since the parents were not vaccinated against pertussis and they would not vaccinate their daughter until she was 1-year-old, they should avoid contact with pertussis and measles. For example, they should avoid frequenting children who go Rudolf Steiner schools, and these children's parents, as they tended to be people were not vaccinated and could thus expose their daughter.*

Hesitant parents who had vaccinated their children reported employing CAM therapies as a means of mitigating the perceived risks that the vaccine adjuvants incurred upon their children's bodies. Mrs. Godet pursued "homeopathic draining" following her daughter's vaccination. She described, "You give her the homeopathy in order to evacuate the vaccine from her blood so that there aren't any other unintended effects." She obtained these homeopathic granules from the pharmacy and gave them to her daughter one month after each vaccine.

### 3.1.3 Public health framings and desires for individualization

Parents were aware of vaccination being promoted by public health authorities as a normative medical practice. Mrs. Piccard, who vaccinated according to the recommendations and expressed no reservations around vaccination, noted how her pediatrician had presented vaccinations as a standard protocol, "You can sense that it's organized (...) and that it's planned out, even for parents who have not yet accepted vaccination." Mrs. Chappuis criticized how public health authorities presented vaccination. She linked her skepticism and desire for balanced presentation of "the facts" to her higher education, "The Swiss Federal Office of Public Health is pro-vaccine. They say that you need to vaccinate. For me, I don't know if it's because I pursued higher education, but I like to be able to weigh the pros and the cons. I like when all sides are presented to me. I don't like just receiving one side of the story."

Many hesitant parents expressed a desire for individualized approaches to vaccination, such as being able to consider them on a vaccine-by-vaccine, case-by-case basis for their children. These parents often expressed desires to have more specific information about the diseases against which each vaccine could potentially protect and what the "true risk" of vaccinating or not vaccinating one's child in Switzerland.

In two vaccination consultation observations, one with Dr. Buchman (GE-CH, TCM and acupuncture) and one with Dr. Caspari (FR-CH, pediatrician) we observed a simple, yet innovative approach for providers to be able to individualize the vaccination information they provide to parents. In both cases, the providers wrote down the child's name on a blank sheet of paper, and didactically wrote the names of the recommended vaccinations, one-by-one as they discussed the parents' different options. In both cases, the vaccinations were offered according to the official vaccination schedule, but they were handwritten and explained individually by the doctors. In both instances, the parents were receptive and appeared to appreciate this approach.

## 3.2 Relationships between CAM, biomedicine, and (non)vaccination

When it came to parents' choices of CAM or biomedical doctors for their children, participants seldomly discussed a direct, linear relationship between their use of CAM or biomedicine and their vaccination decisions. Several parents described choosing doctors based upon recommendations from social networks and positive or negative communicative experiences with HCPs. In the following paragraphs, we discuss some of the patterns involving parents' choices of CAM or biomedical practitioners in relationship to vaccination decisions.

When discussing vaccination, parents had preconceived notions about biomedicine's relationship with pro-vaccine attitudes and CAM's relationship with anti-vaccine attitudes. Mrs. Galland explained why she did not consult with CAM providers, "In general, I think they're all against vaccination. So, I don't really need to see them to know their opinion." Others described biomedical doctors' roles in vaccinating with public health goals in mind. Mrs. Diesbach described how she thought biomedical doctors wanted to "absolutely vaccinate" because "the doctor's role is to eradicate disease."

For vaccine accepting parents, the norm appeared to be for parents to seek cares from a biomedical pediatrician for their children's developmental checkups and cares. These parents discussed not having actively looked for a doctor for their children. Several were arbitrarily assigned a doctor at the hospital after delivery. Others explained how they had chosen a doctor who was within close proximity to their homes. Those who accepted vaccinations described the vaccination decision as a normal step in their children's healthcare. Mrs. Piccard described why she had had her son vaccinated, "My brothers and I were all vaccinated, and everything was fine. There wasn't really a particular reason that pushed us to vaccinate."

Some parents described having made the conscious choice to consult with CAM providers because of their own intentions to not vaccinate their children according to vaccine recommendations or due to their vaccine hesitancy. These participants described how they sought to avoid confrontation or being lectured by HCPs. When asked about her choice for her children's pediatrician, Mrs. Humbert described how she had decided to "choose a homeopathic pediatrician from the beginning who was open to [non-vaccination]. It was especially about that."

Other parents did not link their choice of CAM pediatricians directly to their vaccination attitudes but rather explained seeking cares from a CAM provider because of parents' perceived associations to "natural, chemical-free" approaches. Interestingly, we witnessed several parents who were not familiar with the specific CAM practices or services of the providers they were seeking. For example, Mrs. Sandoz explained her choice of an anthroposophical pediatrician, "I was looking for a classically trained pediatrician who also offered alternative medicine because I'm not in favor of medication. I prefer both my own and my child's immunity to develop on their own before taking medicine or ingesting chemicals. (...) So, I looked around. I didn't know much about anthroposophy. I read a little bit about it, and it suited me."

We observed a similar finding in a consultation between Dr. Schmidt and a mother of a 5-day-old baby:

*Dr. Schmidt explained to the mother that, as an anthroposophical provider, he used integrative approaches, meaning that he combined biomedical approaches with complementary approaches. The mother said that she had never consulted an anthroposophical provider but that she knew some of his patients. The doctor smiled and said, 'Ah, you know some of my patients?' She nodded, saying that she did and that she had heard good things about him. She explained how she was happy to hear from her friends that there were no protocols with him and that it was the family's situation that was most important.*

Several parents who expressed reticence about vaccination described having established lasting relationships with their children's biomedical doctors. In these cases, the pediatricians had either convinced the parents to vaccinate more than they had originally intended or were willing to accept the parents' decisions to delay or not vaccinate without insisting too heavily on the issue. In the case of Mrs. Galland, who had decided against the HPV vaccine for her teenage daughters, she found support for her decision from the daughters' pediatrician, "I asked the pediatrician at the time. She told me that if she had daughters, she wouldn't do it."

### 3.3 The intersections of trust, affect, and choice

Unsurprisingly, and in support of other research regarding vaccinating decision-making, participants' trust in their HCPs was clearly a major determinative factor for participants' vaccination decisions (Benin et al., 2006; Ames et al., 2017). Parents overall cited trust in their provider as being one of the most essential aspects for them to be able to meaningfully engage with health information provided to them.

Some parents' trust in their children's doctors outweighed other sources of information that might have otherwise influenced their vaccination choices. Mrs. Crevoisier described this:

*I had skimmed 1 or 2 books which I closed rather quickly. In one, it would say one thing. In the other, it would say exactly the opposite. (...) So, I said to myself, 'It's going to be my trust in the homeopathic doctor. He is my reference point. He is my partner for my children's health.'*

Other participants' trusting relationships with their doctors brought them to vaccinate. For example, Mrs. Godet, who self-described as vaccine hesitant, explained, "We are trusting, nonetheless. I trust my pediatrician. So, if she tells me that we should vaccinate, I think it's fine." Many others echoed such sentiments, with Mrs. Bouvet completely trusting her pediatrician's recommendations to vaccinate according to the official schedule. She explained, "It's the pediatrician's profession. It's important to trust professionals."

### 3.3.1 Affect, emotions, and social proximity

Parents' accounts of their experiences with HCPs and engagement with the vaccination decision-making process were generally described in emotional terms. Parents' evoked affect, or their general sense of comfort or discomfort, as important elements in their clinical encounters for their children's health. Mrs. Piccard described her trusting relationship with her son's pediatrician by simply stating that she had a "good feeling" about him. Conversely, other parents particularly focused on negative emotions and affect they experienced in interactions with their children's doctors.

Ms. Besse's decision to consult with a homeopathic pediatrician resulted from previous discussions with her son's first pediatrician who had referred to her as an "unfit mother" and mentioned the death of her son as a potential consequence of non-vaccination. At first, the original pediatrician was accepting of Ms. Besse's wishes to not vaccinate. However, the doctor changed her mind after talking to the son's father. Ms. Besse explained,

*I switched pediatrician's recently (...). [The first one] had been very open to my choice to not vaccinate, but then, the father talked to her about it again. At our last check-up, she said to me, 'But you don't realize, he could die!' That really upset me because, while I accept that a pediatrician can disagree with me, she shouldn't make me feel guilty. It's not the role of a doctor. I also need someone with whom I am at ease.*

Ms. Besse further explained her decision to leave this pediatrician, "I don't want to have my stomach in knots every time I go see her because I have certain ideals!" She was considering sending a letter to her son's former pediatrician in order to explain her departure from her practice because, during their tense exchange, Ms. Besse was so shocked and emotional that she "did not have the guts" to say something. At the time of the interview, Ms. Besse had not yet consulted with the homeopathic pediatrician but found her after perusing a Facebook group created by and administered by vaccine skeptical mothers in the French-speaking region of Switzerland. Ms. Besse explained how group members circulated lists of the names of doctors, commonly CAM providers, who were friendly to non-vaccination.

During a vaccination consultation with Dr. Buchman, we witnessed a mother discuss her difficulties in finding a HCP with whom she could satisfactorily discuss vaccination for her children. After vaccinating her son as recommended, the mother described how he had begun to cry more than before, and with each subsequent vaccination, he had additional symptoms, such as vomiting, fever, and sometimes being unresponsive. She explained to Dr. Buchman how the first biomedical pediatrician had not been supportive when she mentioned these symptoms and described feeling very "left alone." She found a second pediatrician as a result. However, her son's non-vaccination became a point of tension in her relationship with the second pediatrician. The pediatrician had told the mother her that not vaccinating was "irresponsible and harmful," which disappointed her and made her lose trust in him. The mother then explained how she had considered going to a shared pediatric CAM practice of "well-known non-vaccinators," but since she is considering doing some vaccinations, she was seeking a provider who could advise her.

The comment about being an "irresponsible mother" echoes what other parents described feeling when other people evaluated their choices. These participants described the impression that being criticized for the decisions they made for their children's healthcare was, by extension, a

criticism of themselves as parents. Such comments brought this mother, whose logics of care of being a good mother brought her to be proactive and assert her expertise about her son's health to consult with Dr. Buchman.

Several parents expressed a desire to be considered to be on the same social level as doctors, explaining how the social distance in biomedical offices could be off-putting or distract from the parent-provider relationship. Mrs. Chappuis explained her preference for her children's homeopathic pediatrician after having changed doctors, "There's just something so human about him. (...) It's kind of a silly detail, but he doesn't wear the white doctors' coat. So, you really have the impression that you're talking to a peer, like someone who is on your level. (...) It's like we're having a coffee together. There's no judgement. It's really pleasant."

On a similar note, many parents considered their children's HCPs outside of their roles as health practitioners by seeking to know how these professionals vaccinate their own children. In other words, they wished to engage with their practitioners not only as practitioners, but as fellow parents. Mrs. Lopez, for example, explained how she asked her CAM practitioner about his own parenting choices, "The doctor who practices alternative medicine told me that it was the parents' choice. After that, I asked him if he vaccinated his daughters. He told me that he did." Some parents sought vaccination advice from their midwives who had children in instances when their child's doctor was not a parent. Mrs. Godet, for example, explained being interested in knowing what her midwife thought because she had the "motherly element" that her pediatrician did not have.

### 3.3.2 Choice

Discussions about vaccine mandates and parental decisions were largely framed against recent debates about vaccine mandate laws in Switzerland's neighboring countries Italy, France, and Germany. During interviews with parents, and in observations of medical consultations, the issue of choice was often evoked in relationship to the Swiss context, where parents vaccinate on a voluntary basis. Many parents viewed the ability to choose vaccinations independently from medical and governmental recommendations in a positive light. Mrs. Godet explained, "In Switzerland, it's true that we have the choice. I think that it shouldn't be allowed to impose things like that, particularly when we're not really aware of what the content of vaccines are. Most people vaccinate for certain things without always knowing what the disease is and what the risks are."

We observed as one mother described her concerns about recent French mandate laws to Dr. Schmidt (FR-CH, anthroposophic medicine). She was a French citizen who crossed the border to work in Switzerland. She told Dr. Schmidt that her daughter would be subjected to the 2018 French mandates, but she was trying to change their official residence to Switzerland so that her daughter could go to a Swiss public school, where she would be exempt from vaccine mandates.

Mrs. Martin, a mother of 3 unvaccinated children, described how her biomedical pediatrician had earned both her trust and loyalty by respecting her choices:

*[The pediatrician] is a good listener, and she respects my choices. That's not always the case with doctors. And for that, I thank her. We continue going to see her because we're happy. When I told her that we weren't going to vaccinate, she gave me her arguments. She made sure that I had understood the consequences of my decision.*

Mrs. Goff, a mother of 2 partially vaccinated children, described the relationship she had with her children's biomedical pediatrician, "What's nice is that there wasn't any pressure. She didn't push me to do anything. I know that she would be in favor of vaccination, but she doesn't force. She lets parents have a certain amount of autonomy. We are free in our decision-making."

In the following observation notes, we provide a narrative account describing how two undecided parents explained to Dr. Welty (GE-CH, anthroposophic medicine) why they chose him as a pediatrician for their 4-week-old baby. At this point in the consultation, they were finalizing a 15-minute discussion about vaccination:

*Dr. Welty said that he had not solved their problem. The mother said that he did not have to. The doctor told her that he could not make the decision for them. She replied by explaining that they had chosen to come see him specifically because he did not pressure parents into making decisions.*

It is interesting to note how, in the Swiss context, where vaccinations are on a voluntary basis, some parents nonetheless perceived doctors' abilities to force patients to vaccinate. Mrs. Chappuis, for example, explained how she felt forced to vaccinate by her daughter's pediatrician:

*She forced me to vaccinate against the flu and whooping cough, but I'm absolutely against the flu vaccine. I had my little 3-week-old baby in my arms, and the doctor said, "You know, if she gets the flu, she can die. If she gets whooping cough, she can die, too. You're not vaccinated against these diseases." (...) She said to me, "If you don't do it, your child is going to die." What's a mother supposed to do? You don't want your child to die.*

After a visit to her own kinesiologist for recurring eczema, Mrs. Chappuis reflected further upon her own flu and whooping cough vaccinations and the perceived consequences for her daughter. She explained:

*The kinesiologist did everything that she normally does for my own treatment, and, since my daughter was colicky, she said to me, 'If you want, I can have a look at her. I can see if I can help her.' Then, she put her hands on her to see the different energies. Actually, I don't really know how it works. And she said to me, 'But, you've had your little daughter vaccinated?' I told her, 'No, I didn't have her vaccinated.' She said, 'It feels like she's been vaccinated. (...) It's very strange because she really has the energy of a vaccinated child.' So, I said, 'The pediatrician vaccinated me.' And she said to me, 'Ah, that must be it. You breastfeed her, so, it went through your milk.'*

*That really upset me. I thought, 'This pediatrician forced me to get vaccinated, but she didn't say that it would go into my breastmilk.' (...) I really had the impression that I had been betrayed and that she didn't explain everything to me.*

This issue would eventually culminate in Mrs. Chappuis's decision to leave her daughter's pediatrician and seek cares from a homeopathic pediatrician. While the use of force in the above-mentioned case is debatable, it was in hindsight perceived as such by Mrs. Chappuis due to the doctor's evocation of her daughter's potential death. The doctor's appeal to her responsibility as a mother and her daughter's risks elicited an emotional response from her, prompting her to *exit* the relationship she previously had established with this pediatrician. Mrs. Chappuis described how her children's homeopathic pediatrician had earned her trust by not taking her "for an idiot" and "taking the time to have a discussion." She explained how the pediatrician engaged in the vaccination consultation without judgment, "He told us right off, 'I happily vaccinate. I am willing to not vaccinate if you don't wish to do so. There is no judgement. It's really you that decides. (...) We really were able to make an informed choice. It was a real choice. It wasn't imposed upon us.'"

## 4 Discussion

This article has described parental vaccination decision-making at the intersections of CAM and biomedicine in Switzerland. Many hesitant and rejecting parents demonstrated "logics of care" (Ward et al., 2017) comparable to neoliberal, intensive parenting practices described in other research (Hays, 1996; Reich, 2014). The hesitant parents in our sample particularly described their healthcare practices for their children by denoting the importance of natural, chemical-free, and minimal Western medication regimens. Similar to the findings of Attwell et al. (2018), parents did not always describe a linear relationship between their use of CAM or biomedicine and (non)vaccination. Some vaccine hesitant and rejecting parents described biomedicine and public health authorities as being influenced by pharmaceutical industry, profit-seeking and associated them with biased presentation of data in favor of vaccination and as promoting *one-size-fits-all* approaches to vaccination. CAM providers, on the other hand, were generally perceived of as offering a space where parents could seek out "neutral" information sources, where they would not be unduly influenced in making their vaccination decisions, and where they would be accompanied in their children's healthcare, regardless of their vaccination decisions.

We particularly focused on parents' transition from seeking healthcare services via biomedical practitioners to seeking the services offered by CAM providers, benefiting from Hirschman (1970)'s concepts *exit*, *voice*, and *loyalty*. The parents who chose to exit relationships with biomedical doctors in our sample did not necessarily do so as a result of overt epistemological differences between themselves and their children's biomedical providers. In effect, several vaccine rejecting and skeptical parents who demonstrated the above-mentioned logics of care had maintained relationships with their children's biomedical pediatricians, despite parents' nonadherence to official vaccination schedules.

Our evidence has shown that the enactment of *exit* and *voice* options generally revolved around issues related to trust, choice, and affect vis-à-vis CAM and biomedicine in clinical encounters. As a means of expressing disagreement or dissatisfaction, some parents exited their relationship with their children's biomedical providers. Parents who chose to *exit* relationships with biomedical doctors perceived CAM providers as being able to offer a "neutral" space where they could discuss vaccination in an unbiased, nonjudgmental way. It should be noted, however, that as part of the provider selection process, hesitant parents in search of the "truth" about vaccination were sometimes skeptical about embracing CAM as a valid option due to preconceived notions about CAM providers being categorically anti-vaccine.

Parents ability to enact the *voice option* to express dissatisfaction was rarely evoked in parents' discussions of their clinical encounters or in our observations of vaccination consultations. This might be due, in part, to patients' fear of being labelled as "difficult" when expressing disagreement in physician-provider interactions which have been characterized as being composed of differential power balances between patients and doctors (Frosch et al., 2012; Dubé et al., 2016).

Research does show, however, that parents and anti-vaccine and vaccine safety advocacy groups provide platforms for parents to enact *voice options* for expressing dissatisfaction with vaccination consultations or vaccinations themselves (Blume, 2006; Navin, 2015; Sobo et al., 2016). The parents in our sample explained how they themselves had expressed negative experiences, or had heard similar testimonies, around vaccination and negative clinical encounters, within their social networks.

The concept of *loyalty* between parents and their doctors was primarily contingent upon the existence of a trusting relationship having been established and maintained. As we have shown with the example of Mrs. Martin's relationship between the biomedical pediatrician of her three unvaccinated children, parents' loyalty to their children's doctors did not necessarily depend on sharing similar epistemologies about medicine and vaccination, nor on agreement about a correct course of action for children's healthcare. Rather, it revolved around parents' feeling of being taken seriously, listened to, and positive affect in clinical encounters.

The non-hesitant, fully vaccinating parents in our sample expressed trust, and by extension, loyalty to their biomedical pediatricians in this study. This is not surprising since there were likely few opportunities for *epistemic friction*, to borrow from Navin (2015), in these interactions. Parents who were vaccine hesitant or rejecting likewise expressed trust towards their CAM providers. This is not surprising either, as previous qualitative research has shown that CAM provider approaches in Switzerland likely appeal to the above-described logics of care of vaccine hesitant and rejecting parents. CAM providers in Switzerland have been shown to frame vaccination decisions as choices at individual and family levels by taking time to understand parents' wishes, involving them in vaccination decisions, and taking their concerns seriously (Deml et al., 2019b).

Whereas parents' enactment of *exit*, *voice*, and *loyalty* options in making their decisions points to recurring patterns that emerge in the expression of parents' (dis)satisfaction with vaccination consultation services, the qualitative evidence we have presented here cannot attest to the overall prevalence of such behaviors. Our sampling strategy might have biased our focus on parental *exit* from relationships with biomedical providers since parents who had experienced negative interactions with HCPs might have been keen to share these experiences and have their stories heard. Additional quantitative work could explore these patterns on a larger scale.

The use of the concepts of *exit*, *voice*, and *loyalty* might also be too simplistic when applied to healthcare decision-making. Whereas some parents explained how they had enacted *exit* from their relationship with biomedical providers, it would be a stretch to say that they had exited biomedicine completely. Most parents who used CAM therapies or services after enacting the *exit* option described how they nonetheless retained a relationship with biomedicine for other health-related issues. As previously mentioned, parents' enactment of *voice* did not always take place during clinical encounters. If researchers wish to pursue parental use of *voice* around vaccination (dis)satisfaction, further research attention would benefit from focus on parents' social networks, parental use of the

Internet, particularly forums where one can create and upload content, and in research approaches related to health social movements. Finally, the concept of *loyalty*, and *being loyal* to one's HCP might be too strongly connoted if we wish to use it as a proxy for trusting relationships.

## 5 Conclusions

Our findings provide practical implications for HCPs who are likely regularly confronted by parents engaging in intensive parenting practices and who might be vaccine hesitant. Other research has shown how such clinical encounters can elicit dilemmas, challenges, and dissatisfaction for providers of biomedicine (Kempe et al., 2011; Kempe et al., 2015; Philpott et al., 2017; Deml et al., In Revision). From a public health perspective, public health authorities have recognized that HCPs "remain the most trusted advisor and influencer of vaccination decisions, and they must be supported to provide trusted, credible information on vaccines" (WHO, 2019). Some of this support will come from further understandings of vaccine hesitant and rejecting parents' rationales.

First, HCPs could benefit from an understanding that parents who express concerns about vaccination are not categorically anti-vaccine, do not simply lack information, and that their questioning is in search of information in the best interest of their children. Most parents who did not vaccinate according to the official schedule in our sample reported not being opposed to the idea of vaccinating their children and, similarly to Reich (2018)'s findings, prided themselves in their questioning of recommendations as part of their intensive parenting practices.

Second, HCPs who are dismissive or who do not engage with parents' vaccine hesitancy miss an opportunity for conducive dialogue that acknowledges parents' commitment to their children's health and well-being. Most of the parents in our sample reported seeking out the "truth" about vaccinations, the diseases they protect against, and the "real risks" they incur by choosing to vaccinate or not. Similarly, HCPs who counsel CAM-oriented parents do not necessarily need to align themselves with parents' inclination towards natural, chemical-free, and anti-Western medication stances in consultations. As we have documented, several parents reported not being fully committed to CAM as their only healthcare option. Some parents noted that they did not fully understand certain CAM approaches but appreciated having options for what they perceived as "natural" and alternative approaches to biomedicine. Similar to Attwell et al. (2018)'s assertion, we suggest that HCPs could, in encounters with hesitant patients interested in CAM, "adopt a tone of curiosity and partnership, seeking to better understand the core concerns with vaccination and seeking whether there is any room for change in position or compromise" (p. 113).

Third, HCPs might underestimate their symbolic roles in representing biomedicine in their interactions with parents. For many parents, their children's pediatricians are among the first professionals with whom they engage as they begin making healthcare decisions for someone other than themselves—their children. Parents' framings of their interactions with their children's HCPs demonstrated the importance of establishing "good feelings" with their providers in order to establish trusting and long-lasting relationships.

With the assumption that CAM and biomedicine are equitably available via reimbursement through mandatory health insurance schemes within the free market of healthcare in Switzerland, it will be important for researchers and clinicians to understand what parents come to perceive of as the quality of the services that biomedicine and CAM can offer and what brings healthcare consumers to enact the mechanisms of *exit*, *voice*, and *loyalty* around the issue of vaccination. As our qualitative evidence has shown, the quality of vaccine consultation services for parents was generally experienced via trusting relationships, affect, emotion, and social proximity, with the understanding that parents desired the best health outcomes for their children.

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## Chapter 6

# Discussion, Conclusions, and Implications for Future Research

In Chapter 1 of this thesis, I introduced a guiding theoretical framework to set the basis for research into the processes involved behind the multifaceted, complex phenomena of vaccine hesitancy and under-immunization in Switzerland. Different strands of these theoretical considerations have been interwoven into the arguments of the previous chapters and discussions of the study's empirical findings. The framework largely dealt with my propositions for a social understanding of knowledge, the coproduction of health and medical knowledge, and a critical view of health literacy which is rooted in a social practice-based approach. I borrowed from different areas of scholarship and recall here for the reader how *symbolic interactionism* (SI) from social science research has been a useful heuristic of understanding how people come to make health-related decisions. I used the definition from Blumer (1969) who argues that SI rests upon “three simple premises” (p. 2) aiming to explain human behavior: 1) people act towards objects based upon the meanings that they attach to these objects, 2) the meaning attached to objects derives from people's interactions with others, and 3) these meanings are negotiated through an interpretative process used by people as they produce meaning related to objects. While conducting this research, I found support in the agency-structure dialectic (Giddens, 1991; Abel & Frohlich, 2011) which allowed me to pay attention to the interplays of the capabilities of social actors (*agency*) to become empowered to interact with the governing *structures* related to health (medical institutions, norms, social networks, and beliefs). A dialectical understanding of agency and structure recognizes how these concepts both enact upon, and are enacted upon by, each other.

In the paragraphs that follow, I seek to revisit this framework in order to discuss some of the recurring elements that repeatedly cropped up during the conduct of the study, both from study participants themselves during data collection, and from other health researchers, clinicians, and public health advocates in discussions that resulted during formal and informal disseminations of study results. One of my goals of including the following discussion is to call attention to some of the recurring ideologies that commonly present themselves in public discourses and public health responses to vaccine hesitancy and under-immunization. The following discussion is informed through the combination of our data collection, readings of relevant literature, and discussions with colleagues, family, and friends since I began undertaking this research almost 3 years ago.

For specialists of vaccine hesitancy, which has been developing into a growing research field in and of its own right in the past several years, many of these arguments will not necessarily be novel or surprising. For those who are less familiar with the ever-growing body of literature on this subject, some of these ideas and criticisms might appear to be unnecessarily provocative or critical of biomedicine and public health approaches and health promotion approaches to vaccination. My aim is not to be unproductively critical, as I recognize that many of the assumptions about approaches to addressing vaccine hesitancy are aimed at mitigating the potential of dwindling vaccination rates and are rooted in desires to achieve better health outcomes. Those who are skeptical of the necessity, efficacy, and safety of vaccination generally also share the same desire of achieving better health outcomes. We should not underestimate nor overlook the shared goal of doing what ‘is best for children’ (Wang et al., 2015) in discussions around public health and clinical approaches to vaccination.

In the next sections, I will reflect upon these recurring elements with the aim of reconsidering public health and clinical approaches to addressing vaccine hesitancy. First, I will discuss how there are often multiple competing knowledges that are at play regarding vaccine hesitancy and non-vaccination. Second, I will touch upon knowledge-deficit models and approaches that assume that non-vaccinating parents just simply lack the knowledge to make the “right decision”: to vaccinate. Third, I will expand upon other researchers' call for society to move beyond polarizing vaccination discourses (Brunson & Sobo, 2017) and point to the importance of the language we use on these often sensitive issues. Finally, I touch upon the strengths and limitations of this qualitative inquiry into vaccine hesitancy and under-immunization in the Swiss context.

## 1.1 Vaccination decision-making at the intersection of different knowledges

As epidemiologists and public health researchers, we are taught that there are hierarchies of knowledge and differences in the types and qualities of evidence that should inform our thinking, research, and health policy recommendations, with the noble goal of pursuing “evidence-based” practices (Guyatt et al., 1995; Sackett et al., 1996; Burns et al., 2011; Murad et al., 2016). Whereas healthcare professionals are trained to think about evidence in terms of these hierarchies, many lay people and individuals, to the frustrations of many healthcare professionals, do not conceive of health, illness, well-being, and risk decision-making similarly (Borkman, 1976; Caron-Flinterman et al., 2005; Castro et al., 2019).

This is where the distinction between Mode 1 and Mode 2 knowledge production, inspired from Science and Technology Studies (STS), from Chapter 1 becomes relevant again. I here remind the reader that according to Gibbons et al. (1994), Mode 1 encompasses *traditional knowledge production*, in which knowledge is “generated within a disciplinary, primarily cognitive, context”, and Mode 2 refers to knowledge which is “created in broader, transdisciplinary social and economic contexts” (p.1).

In line with Gibbons, the focus of this research has been on *knowledge* coproduced in Mode 2, such as health-related knowledge production, has been extending outside the disciplinary realms of the biomedical sciences, and vaccine hesitant proponents tend to call into question biomedical discourse related to vaccine safety, efficacy, and need. The use of the term *knowledge* in this research does not necessarily indicate evidence-based, scientific discourse. Rather, the use of the term indicates what individuals perceive as being information on which they can base their health-related decisions. Furthermore, articulated this way, knowledge involving vaccines can be more broadly understood while considering the multiple iterations of the ways of knowing (medical, evidence-based, experiential, and lay), which ultimately sheds light onto the competing knowledges involved regarding vaccination.

In our modern era dominantly characterized by “fake news” and “alternative facts” in public discourses, O'Connor and Weatherall (2019) provide a timely and refreshing understanding of how “false beliefs” spread. Rather than falling into overly simplistic explanations in which the propagation of false information is purportedly due to individuals’ cognitive and psychological shortcomings, these authors point to social processes by which groups collectively come to learn, share, and disseminate knowledge. Their analysis involves the study of *epistemic communities*, or “communities of people trying to gain knowledge about the world” (p. 13). Through the use of network analysis modeling on scientific epistemic communities, O'Connor and Weatherall show how social mechanisms relating to conformity, strength of social ties, (mis)trust, values, polarization, and outside influence can disrupt and contaminate epistemic communities’ pursuit for knowledge about the world. Their main discussion concerns how false beliefs can come to spread within scientific groups, which leads them to point to the ease with which false beliefs can spread in Mode 2, particularly with the rise, popularity, speed, and reach of the Internet and mass social media sites. They explain,

“Most of us are not trained as scientists, and even fewer have jobs in which they are paid to do research. But we are often trying to figure stuff out about the world—and to do this, we use the same basic kinds of reasoning that scientists do. We learn from our experience—and, crucially, we learn from the experiences of others” (p. 150-151).

Navin (2015)’s philosophical and ethical critique into the values of vaccine refusal examines parents’ (particularly mothers) engagement in epistemic communities that are resistant to mainstream biomedicine. Through his analysis of mothers’ *epistemic virtue*, which is “inquiry about medicine as a disposition which facilitates the acquisition of empirically grounded medical knowledge” (p. 22-23) and *epistemic vice*, which refers to “a disposition which inhibits the acquisition of empirically grounded medical knowledge” (p. 23). Navin’s analysis into vaccine hesitant communities’ epistemic positionings calls attention to the justifiable rationales, or *epistemic virtues*, of these mothers in their encounters with pediatricians. These *epistemic virtues*, he argues, are justified via feminist critiques which encourage women to question the traditionally authoritative, paternalistic, and male dominated practice of medicine which has historically asserted control over women’s bodies. He equally argues that mother’s skepticism towards vaccination which is rooted in other criticisms of questionable

practices in modern medicine, such as doctors' over prescription, financial profit-seeking, and real concern with risk aversion for their children, serve as an example of epistemic virtue. However, Navin critically points to parents' engagement in *epistemic vice* in situations in which vaccine denials "avoid interactions with mainstream pediatricians who may challenge their views. A disposition to avoid potentially productive epistemic 'friction' is not conducive to acquiring medical knowledge" (p. 23).

As we have shown in the previous chapter about parents' vaccination healthcare and vaccination choices at the nexus of CAM and biomedicine, parents engaged in both epistemic virtue and vice, as some were comfortable with epistemic friction with their selected doctor for their children's healthcare in the search of medical knowledge. Others, to borrow again from the terminology of Hirschman (1970), expressed their dissatisfaction with the clinical encounter through the use of *voise* or *exit*, to the detriment of loyalty to the initial healthcare provider, in order to enter into a different relationship with other healthcare providers where these parents perceived less potential for epistemic friction.

Virtually all participants in this study engaged in Mode 2 knowledge production around vaccination, as only a small minority of participants, primarily biomedically trained doctors, were involved in biomedical knowledge production that would fall into the Mode 1 category. The healthcare providers, CAM and biomedical doctors alike, were heavily reliant upon vaccination knowledge that was produced in Mode 1 by experts on vaccination, immunology, and public health. As evidenced in Chapters 3 and 4 of this thesis, practitioners of CAM and biomedicine cited the Federal Office of Public Health vaccination schedule recommendations, medical literature, their biomedical training, scientific experts, and continuing education training programs as being their sources of information about vaccination for their discussions in clinical encounters.

Some biomedically trained pediatricians diverged in their opinions about Mode 1 knowledge about vaccination. Several questioned the necessity of pneumococcal and meningococcal vaccinations in the Swiss context. Others particularly wondered about the age appropriateness for hepatitis B and HPV vaccinations. These doctors questioned their responsibility in administering HPV and hepatitis B vaccines and in discussing sensitive topics, such as sexuality, with their younger pediatric patients, expressing a preference for these decisions to be made instead with parents, via school recommendations, or with gynecologists. That some biomedically trained physicians expressed vaccine hesitancy themselves is not surprising, as other research has shown an increasing need to be aware of vaccine hesitancy among healthcare professionals (MacDonald & Dubé, 2015; Verger et al., 2015; Karafillakis & Larson, 2018).

CAM providers likewise cited being dependent upon Mode 1 produced knowledge, but as argued in Chapter 3, demonstrated being comfortable in calling public health arguments about vaccination into question and instead opting to concern themselves with individual patients' preferences, contexts, and choices around vaccination by providing individualized advice, and not necessarily recommendations, to parents in their decision-making process. This research also demonstrated how CAM providers' perspectives were sometimes at odds or doubtful about the presentation of public health recommendations. I here re-cite Dr. Ferrand, a homeopathic pediatrician, to demonstrate his critique of biomedical presentation of facts:

*(...) the FOPH's information is really good. But, when it comes to some of the grey areas, we find ourselves in a type of magma of information that is very, very difficult to sift through. We kind of have the impression that the FOPH and the Vaccination Commission only shows studies that are [unfinished sentence]. There are studies showing there are maybe complications. Scientific honesty would have it so that those studies are also shared so that we could have that specific element. As a result, we must look further than what the FOPH tells us.*

Other CAM providers discussed approaches that were complementary or alternative to biomedical approaches to vaccination. Some, for example, expressed favor for children contracting childhood diseases as part of their developmental growth, citing anthroposophic philosophy attributed to Rudolf Steiner's way of thinking. Others questioned if the reporting practices for adverse vaccine events accurately represented the reality of the number of vaccine-related adverse events, citing their clinical experiences and patients' negative experiential knowledge with vaccinations. Although not participants in our study, a commonly cited resource by parents and some providers, that was associated with CAM and critical vaccination attitudes, was a book entitled *Qui aime bien, vaccine peu!* [Rough translation: *Those who love their children, vaccinate little!*] (Berthoud et al., 2009). This

book was written by a group referring to themselves as the Medical Group of Reflection on Vaccinations. This group values their critical positions of knowledge produced by public health authorities and vaccine experts. These authors make vaccine-by-vaccine recommendations, questioning the types of evidence advanced by public health authorities in official vaccination schemes.

When it comes to parents, their decision-making around vaccination is complex and multifaceted, and there is more-and-more research being conducted into parents' confidence, hesitancy, and rejection of vaccination. The multifactorial nature, and lack of a "universal algorithm," (Larson et al., 2014, p. 2155) around the determinants of vaccination attitudes further complicates research into the parental vaccination attitudes and decisions. In one of the earlier comprehensive reviews into vaccine hesitancy literature, Dubé et al. (2013) note social science research's contributions which demonstrate how vaccination decision-making is difficult to disentangle from its larger historical, social, and socio-political contexts. In effect, as their overview shows, and subsequent research has continued to demonstrate, perceptions of vaccinations are tied into individuals' past experiences with healthcare systems (Busse et al., 2011; Dubé et al., 2016; Attwell et al., 2018b), perceived norms and discussions around vaccination within social networks (Brunson, 2013), media press reporting and coverage of vaccination in public discourse (Mnookin, 2011), the rise of the spread of health-related information on the Internet and users' abilities to produce their own content (Betsch et al., 2012; Betsch & Sachse, 2012; Sobo et al., 2016), different parenting styles and health-seeking practices in the pursuit of the "best" health for one's children (Reich, 2014; Sobo, 2015; Wang et al., 2015; Ward et al., 2017). Research into vaccination decisions also benefits from recognition of the shifting landscapes of healthcare (Deml et al., 2019b; Deml et al., In Revision) which heighten individuals' attention to notions of patients' decision-making based on risk and responsibility as "entrepreneurs" (Lupton, 1995) of their own health in Western societies (Peretti-Watel et al., 2015).

Similar to other studies, parents in our sample include their perceptions around the risks incurred by (not) vaccinating their children into their decision-making process (Raithatha, 2003; Smith et al., 2004; Omer et al., 2009; Reich, 2014; Ward et al., 2017). Other parents had simply heard recurring rumors or testimonies about adverse vaccine events or exhibited vague awareness of vaccine-related scandals, such as the supposed link between autism and the MMR vaccine or between multiple sclerosis and the hepatitis B vaccine.

One participating mother explained how she negotiated with, and selected different sources of knowledge following the premature birth of her son, who was 1 year old and unvaccinated at the time of the interview:

**Mother:** *With his past of not having an easy beginning to his life, I said to myself, 'I really don't want to see him in a state like that again. I don't want him to get the disease, nor do I want him to have any side effects [from vaccines]. In both cases, I don't want to see him again with electrodes and with oxygen. I think that's when I started questioning and looking into things for myself in order to know if vaccination was necessary. Since it was recommendations from the Confederation, I knew I wanted to have another opinion that was maybe less influenced. I think looking into it gave me more doubts than if I hadn't looked into anything. Because I found certain things, and I think it's only human, but I gave more importance to articles that supported my thinking. Even if there were 10 things that contradicted me, I gave preference to the one thing that supported me. (...) And I also read testimonies from people who claimed to have had a side effect from a vaccine, and it's true that that scared me, too.*

Parents overall enacted resources that were available to them in making their (non)vaccination decisions. Oftentimes, such as with the mother mentioned above, these resources had influential impacts on parents' knowledge bases, which brought them to prefer experiential and embodied knowledges, either via their own previous experiences with biomedicine or vaccinations or those of individuals in their social networks, to biomedically available knowledge around vaccination. Navin (2015)'s reflections would refer to such knowledge sorting as a form of *epistemic vice*. However, a social understanding of how different knowledges are enacted and negotiated recognizes how, as Jasanoff (2006) argues, scientific knowledge is "embedded in social practices, identities, norms, conventions, discourses, instruments and institutions – in short, in all the building blocks of what we term the *social*" (p. 3, emphasis in original).

In other words, both healthcare professionals and parents found themselves confronted with various types of knowledges around vaccination, available to them via their social networks, previous

trainings, and life experiences. Further complicating matters was that some groups and individuals activated these different understandings about vaccination, which brought the knowledges to compete with one another for legitimacy as people attempted to seek out the “truth” of the matter. As researchers, we would do well to recognize how groups and individuals engage with different forms of knowledge(s) and recognize that people do not generally reason similarly to the idealized forms of reasoning favored by models of researchers’ hierarchies of knowledge and qualities of evidence.

## 1.2 Critiques of knowledge deficit models and information-only approaches

When it comes to vaccine hesitant, non-vaccinating, or under-immunizing individuals, a common response from clinicians and proponents of preventive public health efforts has been to turn to patient education approaches framed against the backdrop of the knowledge deficit model (Dubé et al., 2013; Kitta & Goldberg, 2017; Smith, 2017). Within this model, the assumption is that these individuals simply lack the necessary information to make the “rational choice,” which, from public health and health promotion perspectives, would be to vaccinate. However, educational approaches to address vaccine hesitancy and increase vaccination uptake have been called into question and often demonstrated as ineffective (Sadaf et al., 2013; Jarrett et al., 2015; Gagneur et al., 2018). Evidence suggests that rationales which are critical of, or do not strictly adhere to, the biomedical model of evidence-based medicine, such as preferences for complementary and alternative medicine (CAM), endorsing spirituality as a source of information, and openness to new experiences, can equally play important roles as predictors of negative vaccination attitudes, *à la carte* vaccination, delays, and refusals (Browne et al., 2015; Wardle et al., 2016; Attwell et al., 2018b).

In discussions on vaccine hesitancy and vaccine uptake, the focus on health literacy, while well-intentioned, is likely misguided due to several of its underlying assumptions. First, health literacy research and models implicitly promulgate normative assumptions about health and well-being. In their widely cited review, Sørensen et al. (2012) define health literacy as follows:

“Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course” (p. 3).

Such a definition implies the existence of a unified body of “health information,” which is to be accessed, understood, appraised, and applied by individuals who are assumed to share a singular vision of health. In other words, health literacy as such does not directly account for “health information” which diverges from biomedical epistemologies.

Second, this definition assumes that individuals share similar, normative goals about health which are in alignment with public health goals and rationales. However, as Lupton (1995) critically describes, public health and health promotion discourses often evoke moral judgements in order to “produce certain limited kinds of subjects and bodies,” (p. 5) by relying “upon the model of the rational, unified self, consciously making decisions about one’s conduct in everyday life in the quest for self-improvement” (p. 8-9). This conception of health literacy fails to account for individuals who do not act or inform themselves in accordance with biomedical conceptions of health in order to achieve “good” health.

Third, recurring conceptions of health literacy do not contend well with postmodern understandings of truth as multifaceted and embedded in dynamic power relationships (Gray, 1999; Paul & Haddad, 2019), particularly when individuals are encouraged to make health decisions in terms of risk calculations. As social scientists have long argued, risk is a social construct and is subjectively imbued with different meanings and values for different individuals and groups (Douglas, 1982; Lupton, 1995). Furthermore, in postmodern contexts, patients are encouraged to be more autonomous in navigating healthcare decisions and systems (WHO, 1986; Armstrong, 2014) while public confidence in science, experts, and institutions is precarious (Giddens, 1991; Burton-Jeangros, 2004; Salmon et al., 2015). Further complicating matters, considerations of risk in health decision-making imply a certain degree of uncertainty about the future, which often elicits emotive reactions, particularly when individuals are

exposed to a multitude of (often contradictory) information (Wang et al., 2015) via the Internet (Betsch et al., 2012; Betsch & Sachse, 2012; Sobo et al., 2016) or their social networks (Brunson, 2013).

Further bolstering the criticisms of the knowledge deficit model in vaccination decision-making are studies that examine the relationship between health literacy, vaccine hesitancy, and vaccination uptake. A systematic review was unable to draw universally valid conclusions about the direct relationship between health literacy and vaccine hesitancy, with researchers noting that the relationship remains unclear and that other factors and social determinants of health, such as country, age, vaccine, and risk perception, as likely mediating factors between health literacy and vaccine acceptance and hesitancy (Lorini et al., 2018).

Additional critiques of the knowledge deficit model come from research that contests its underlying assumptions. For example, a study among 731 parents in Israel found that parents with higher levels of functional health literacy (“the basic ability to read or write,” p. 769), communicative health literacy (“the ability to understand the significance of medical information,” *ibid*), and critical health literacy (“a higher level of skills required in order to critically analyze medical information,” *ibid*) were “more at risk of not vaccinating their children” (p. 768). The authors note how such a finding is contradictory to the knowledge deficit model, which assumes that the more “informed” individuals are, the more likely they are to make choices that promote health.

However, it is rather understandable that vaccine hesitant or skeptical parents, who according to the functional, communicative, and critical health literacy definitions previously mentioned, exhibit behaviors that might confirm or support their initial skepticism. In effect, research shows that vaccine refusers have more knowledge about vaccines than vaccinating parents and that those who delay vaccination or selectively vaccinate have more correct vaccination beliefs than those who adhere to schedules or refuse all vaccines (Benin et al., 2006; Leask et al., 2012; Navin, 2015). In line with previous studies into vaccine hesitant individuals’ information seeking behaviors (Reich, 2014; Dubé et al., 2016; Reich, 2016a, b; Attwell & Smith, 2017; Ward et al., 2017; Attwell et al., 2018a; Attwell et al., 2018b; Enkel et al., 2018; Reich, 2018), the hesitant parents in our study proactively sought out information in search of “the truth” about vaccination while navigating the amount of risk they were incurring upon their children by vaccinating or not vaccinating. An excerpt from one mother exemplifies these common practices and reflections we witnessed with other study participants:

**Researcher:** *And now we are going to talk specifically about how you came to the decision to not vaccinate your child. What guided you in making this decision?*

**Mother:** *It's a difficult question. These are constructions we don't always analyze. Well, I think it was a mix of discussions with people close to us and with friends. Then we made this choice. There is my personal feeling about the matter. There is certainly the social influence from my husband. I'll say that the decision surely came more from me than it did from him. I think I hold the decision closer to my heart than he does. And I think it was kind of a hazy/vague questioning. There were some things I read on the Internet. I joined Facebook groups where they talk about it. I read some testimonies. I think when I was pregnant, I had a discussion with the [anthroposophic] pediatrician in order to know the true risks that we were taking if we didn't vaccinate. So, yeah, I was looking for the most neutral point of view possible. So, I constructed myself like that. It's a decision that, for now, is in favor of not vaccinating. I'm not sure if I answered the question.*

If we consider traditional health literacy definitions around parents’ abilities to access, understand, appraise, and apply health information, it would appear that this mother engaged in all of these activities. This mother clearly did not lack knowledge or resources in order to attempt to understand “health” information. Despite her proactive seeking out of knowledge, she nonetheless came to construct her position that “for now” was “in favor of not vaccinating.” This mother recognized how her search was embedded in social relationships and negotiations, as previous research has demonstrated to be the case (Brunson, 2013). The knowledge she engaged with was not only purely biomedical, evidence-based knowledge, but she also sought out testimonies from other parents. She additionally sought out support from a CAM provider for information about the “true risks” of not vaccinating in search of the “most neutral point of view possible.”

As a critique of the knowledge deficit model for understanding vaccine hesitancy and under-immunization, we have undertaken an alternative approach which seeks to establish the underlying processes by which parents come to make vaccine-related decisions for their children in Switzerland.

Instead of asking questions about the knowledge that parents “lacked” about vaccination, we asked parents on which knowledge(s) they based their vaccination-related decisions and how they went about obtaining such knowledge(s). As alluded to in the thesis introduction, we benefited from Papen (2009)’s social understanding of health literacy. Papen’s approach takes issue with a dominant view of health literacy as an individualized skill that can be quantified through performance measurements. A social practices view on health literacy instead moves past this limited cognitive view of health literacy and considers social actors’ social contexts, the emotional aspects of health, available resources, and the processes through which individuals access and make sense of health information.

### 1.3 The “threat” of vaccine hesitancy and social diagnosis approaches

The World Health Organization (WHO) listed vaccine hesitancy among one of ten important “threats” to global health in early 2019. The announcement called attention to a 30% increase in measles globally, the complexities of non-vaccination, such as complacency, inconvenience in access, and lack of vaccine confidence, and the importance of healthcare professionals (HCP) as “the most trusted advisor and influencer of vaccination decisions,” who need to “be supported to provide trusted, credible information on vaccines” (WHO, 2019).

Listing vaccine hesitancy as a threat to global health provides rich grounds for social analysis. If there is vaccine hesitancy and non-vaccination, this implies the existence of vaccine hesitant and non-vaccinated individuals who embody this threat. I borrow from the social diagnosis model advanced by Brown et al. (2011) and argue that vaccine hesitancy and non-vaccination have become diagnosable at both individual and societal levels. The social diagnosis approach is characterized with three elements: 1) when it comes to the structures affecting diagnostic processes, “[t]reatment and prevention goes beyond the individual, seeking to restructure power, capacity, and community in the surrounding society,” 2) “a social diagnosis approach must contend not only with past and present conditions, but explicitly consider the potentiality of future conditions, specifically because they may have social causes and consequences,” and 3) “a variety of social actors are contributing to the creation of [the] diagnosis. In doing so, they diagnose not only individuals but societies—a practice which is growing more important in light of increasing biomedical uncertainty” (p. 941).

Vaccine hesitancy and non-vaccination are clearly linked to these components: 1) public health efforts activate numerous power structures in promoting vaccination by encouraging higher uptake and mitigating anti-vaccination and vaccine hesitant discourses in the name of the common good, 2) vaccination, a technology whose utilization or under-utilization has both social causes and consequences, is intrinsically concerned with curtailing potential future infections, and 3) the perpetuation of vaccine hesitancy and non-vaccination social diagnoses are promulgated by a multitude of social actors, including medical and public health literature, policy makers, implementation programs, popular discourse and media coverage, HCPs, and patients and citizens themselves (Heller, 2008, Wang et al., 2015).

The scientific literature is rife with examples of how medico-professional experts and researchers engage in the third process of social diagnosis. Rossen et al. (2019), for instance, use Latent Profile Analysis to classify parents into three groups based upon their vaccination attitudes: accepters, fence sitters, or rejecters. Opel et al. (2013) propose a 15-item survey which scores respondents’ levels of vaccine hesitancy on a scale of 0 to 100 and found that higher vaccine hesitancy was positively associated with under-immunization for these respondents’ children and vice-versa. Betsch et al. (2018) propose a model which distances itself from the term vaccine hesitancy by aiming to predict vaccination uptake and focusing on 5 measures (confidence, complacency, constraints, calculation, and collective responsibility). Butler and MacDonald (2015) consider screening of hesitancy beyond individual levels by assessing ways to diagnose vaccine hesitancy determinants in specific subgroups through the Guide to Tailoring Immunization Programmes (TIP), explaining it as, “a diagnostic guide to define and diagnose behaviourally related hesitancy determinants and propose appropriate interventions” (p. 4177). Our research also documented how biomedical doctors in Switzerland “diagnosed” patients according to their level of acceptance or rejection of vaccination (Deml et al., In Revision). One participating doctor even mentioned during an interview how he used to think that non-vaccinators were “mentally retarded” due to their inability to understand biomedical rationales behind the importance of vaccination.

The unfortunate choice of the word “threat” from the World Health Organization likely heightens collective anxieties around the potential for the spread of infectious disease. Additionally, attributing the “threat” itself to vaccine hesitancy, as opposed to the consequences of non-vaccination or to the spread of infectious diseases, creates the potential for vaccine hesitant individuals to be the recipients of stigmatizing discourse that categorizes them into a threatening group. The other risk is that individuals’ skepticism around vaccination becomes pathologized in line with other socio-medical trends that medical sociologists and anthropologists have termed *the medicalization of society* (Conrad, 2007) and *biomedicalization* (Clarke et al., 2010). Philosopher and social theorist Michel Foucault has extensively discussed the power of medicine to create different types of subjects through pathologizing discourses, and social apparatuses, as he has argued in his writings on mental illness (Foucault, 1961) and homosexuality (Foucault, 1976).

The above discussion about categorizing people according to their level of support for vaccination is not meant to categorically criticize the practice. Rather, it is to call our attention to the potential consequences and implications of researchers and clinicians who engage in these practices. As researchers, we need to be sensitive to the potential essentialization of individuals for their perspectives about vaccination, as such perspectives are malleable and amenable to change over time. An example that comes to mind from my qualitative field work involves a mother who recounted her experiences with a pediatrician. After explaining to the doctor that she did not wish to have her daughter vaccinated during that specific consultation, the mother starkly remembers the doctor’s response, “In my daughter’s health booklet, [the pediatrician] wrote, ‘The parents refuse the vaccine.’ I felt like she was accusing me of something.” The mother vividly recalled this instance of having her decision, which she told me could potentially change, was subsequently inscribed into her daughter’s health records. This instance demonstrates this inscription into her daughter’s medical “biography,” to borrow from Goffman (1963)’s discussion on stigma and discursive biographies, was internalized by the mother as a form of social stigmatization about her medical choices as a mother.

As researchers, we will need to maintain vigilance around the use of such classifications and reflect upon the purposes behind classifying individuals according to their vaccination perspectives. It is arguably justifiable to do so when the intent is to design public health interventions for specific sub-groups of individuals according to the reasons underlying their hesitancy or skepticism. In my view, it is not justifiable if the goal is to stigmatize skeptical individuals by labelling them as wrong, ignorant, or underinformed. As a general comment, I am glad to see that these classifications are nonetheless moving away from the long-enduring ‘pro’ vs. ‘anti’ vaccination discourses that have traditionally dominated research and public discourse around the issue of vaccination (Heller, 2008). Brunson and Sobo (2017) have rightfully urged us to move past these polarizations, as they are not conducive to productive or meaningful discussions. Research has consistently shown that conscientious non-vaccinators and categorically anti-vaccine individuals compose less than 2 percent of Western populations (Kahan, 2013; Navin, 2015; Hill HA, 2019). Scholarship has shown that attitudes and perspectives around vaccination range in scope, with attitudes falling along a spectrum, there being ambivalence, and individuals having context-specific and vaccine-specific views. Researchers and clinicians would greatly benefit from an understanding that individuals expressing concerns about the safety, necessity, or efficacy of vaccination are not necessarily categorically anti-vaccination and that our efforts are best spent focusing on the hesitant and questioning groups of individuals.

## 1.4 Strengths and limitations of the study

As with all qualitative modes of enquiry, we as researchers can make no overarching claims about the generalizability or representative nature of the data we have collected as part of this research process. As mentioned in the empirical findings outlined in previous chapters, the qualitative method of observing medical consultations may have had an influence on the consultation observations with the presence of the researcher viewed as intrusive or invoking some form of social desirability bias from the behalf of the study participants. This is an on-going challenge of methodologies involving observations. Other options that seek to mitigate these effects include video recording or audio recording consultations, but these methodologies also imply other considerations and how participants might react to them being proposed. Social likeability bias also likely played a role in participants’ responses to our interview questions. However, through our continued engagement, showing “empathic neutrality,” (Patton, 2002) and the options to probe and prompt at various times

during the interview process (Feldman et al., 2003), we were able to elicit responses that we felt to be accurate representations of participants' perspectives and lived experiences.

We have employed various approaches to triangulate the data collected from in-depth interviews with parents and providers and ethnographic observations of medical consultation observations in an attempt to better encapsulate the "multiple realities" of medical consultations (Barry, 2002). In line with the arguments of this dissertation, the methodologies chosen were flexible and were designed to allow us to understand vaccination as a social object of inquiry and vaccination decision-making as a socially contingent processual behavior. Additionally, we were sensitive to and continually discussed the obtention of theoretical saturation (Morse, 1995; Nelson, 2017) as qualitative data was being collected. We are comfortable in stating that saturation was obtained for the purposes of our study and for the research questions we have asked.

With the various qualitative methods, we were able to tease out and analyze the different social processes at play in parental vaccination decision-making processes and in their encounters with healthcare providers in Switzerland. In conducting this research, we were also able to collect data that allowed us to question and undermine recurring stereotypes and caricatures of CAM providers and users as categorically anti-vaccine. Furthermore, the qualitative research focusing on biomedical providers allowed us to have a better qualitative understanding of how they perceived their interactions with vaccine hesitant and under-immunizing patients and what treating these patients reflected about themselves as healthcare professionals. We were able to demonstrate how biomedical doctors had internalized various pro-vaccination discourses and felt that their patients adhering (or not) to vaccination recommendations had implications for their successes or failures as physicians. The qualitative interviews and observations with CAM and biomedical providers allowed us to delve further into understanding their perspectives, motivations, and constraints when it came to discussion vaccinations with parents.

One reasonable criticism of this qualitative research and its reporting in this doctoral thesis is that we did not actively go out of our way to police the veracity of claims around vaccination made by our study participants. This was an epistemological and ethical choice based upon the research questions which sought to establish the types of "knowledge," as we have previously defined it, upon which different actors based their health-related decisions and recommendations. We did not proactively engage in fact-checking in an attempt to correct, categorize, or label certain types of knowledge as "false," as this went beyond the scope of the proposed research. Our goal was rather to understand, document, and analyze participants' knowledges in their own terms. For a rich, moral philosophy discussion that goes further into depth about such issues related to how adherents to *epistemic communities* can be faced with *epistemic friction* around vaccination, actors may engage in *epistemic vice* or *epistemic virtue* in "truth"-seeking endeavors, I recommend the work of Navin (2015).

Our particular, albeit overtly justified, focus on parents' use of CAM and with CAM providers more than likely turned our conceptual attention to what anthropologists often refer to their epistemological initiative to focus on what is *exotic* or *Other* in whatever social words they are investigating (Fassin, 2001), to the detriment of what is considered to be banal, trivial, commonplace, or otherwise assumed to be universal. Our sampling strategy to focus on providers and parents who employ or use CAM services has more than likely influenced the type of data that we collected. Vaccine hesitant or under-immunizing parents who do not use CAM services were not heavily represented in our qualitative study sample. However, given the popularity of CAM and its integration into the Swiss healthcare system, we find this choice to be extremely beneficial to our overall understanding of the healthcare landscape in Switzerland and parental healthcare choices.

The conceptual comparisons between CAM and biomedicine allowed for a rich consideration and critique of both CAM and biomedical approaches and their roles in vaccination implementation programs. In effect, our findings have demonstrated that whereas CAM does play influential, and sometimes negative, roles in vaccine hesitancy and under-immunization, biomedical providers' approaches in clinical care also merit scrutiny. As we have shown, particularly in our analysis with support from Hirschman (1970)'s *terms exit, voice, and loyalty*, parents' choices around healthcare for the children were rooted in neoliberal mothering (Reich, 2014) and intensive mothering practices (Ward et al., 2017) as they engaged in the healthcare market. Parents generally exercised their choice in selecting healthcare providers for their children based upon the affect (i.e. feeling) and emotions evoked in clinical encounters. Surprisingly, and reflecting other research questioning purely 'rationalist

economic agents' in healthcare settings (Lupton, 1997), the parents in our study often favored the affect (i.e. the overall feeling of the interaction) their providers evoked over their perceptions of the healthcare professionals' medical knowledge.

We therefore agree with Fassin (2001)'s argument where he advocates not only on the exotic or Other population of interest in question (here, it would be CAM providers and CAM users), but we also need to be sensitive to the normalizing institutions and actors of health programs who implement them (p. 306). In our case, we assume biomedicine as the entity implementing vaccination programs, which is where we observed and documented more potential areas for *epistemic friction* (Navin, 2015) between hesitant and under-immunizing parents and biomedical providers than between these similar patients and CAM providers. Our research largely focused on what these frictions implied for the practice of biomedicine in vaccination implementation programs and suggests opportunities for improvement of approaches in clinical practices.

A large strength of this doctoral research being embedded within a larger study (Tarr et al.; Deml et al., 2019a), using a sequential exploratory mixed methods research (Creswell & Plano Clark, 2011), is that the results and concepts we were able to gather and discuss based upon the qualitative research have informed the tools that have been used for collecting quantitative data in a subsequent step. This data will allow our research team to conduct statistical tests behind some of the processes and conceptual relationships we were able to outline as part of the qualitative work undertaken in this research. Furthermore, it is my hope that the qualitative evidence we have gathered, in addition to the conceptual discussion that came about as a result, can serve to inspire other researchers to further refine these concepts and theoretical considerations in other contexts, test their (in)applicability in other settings, and to further our collective understanding of the multifaceted, complex phenomena of vaccine hesitancy and under-immunization.

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