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Austria: a qualitative exploration"

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ABSTRACT

Why are parents in a particular local context choosing to refuse vaccinations on the part of their children? This medical-anthropological study examines parental refusal of childhood vaccinations (a global phenomenon of significant public health concern) through the in-depth examination of a small, localized qualitative sample in Austria's capital Vienna. Research data was collected through semi-structured interviews with 10 parents who refused some or all vaccines on the part of their child(ren), two vaccine-critical doctors, and one anti-vaccination activist, as well as one focus-group session and two participant-observation sessions at vaccine-critical information events. This data was then subjected to semiotic qualitative analysis, resulting in eight major code-groups associated with the act of vaccine refusal: *immune-system concerns, vaccine-damage, risk balance, uncertain efficacy, the hygiene argument, alternative concepts/values, individual responsibility, and power*. Using the words of research participants, these categories are presented, explored and interpreted in order to gain insight into the phenomenon of vaccine refusal in this specific context, with possible implications for clinical practice and/or public policy.

Warum beschließen Eltern in einem bestimmten lokalen Kontext, Impfungen für ihre Kinder zu verweigern? Diese medizin-anthropologische Studie untersucht die Verweigerungshaltung mancher Eltern gegen Kinderimpfungen (ein globales Phänomen von signifikanter Bedeutung für die öffentliche Gesundheit) anhand einer kleinen lokalisierten Untersuchungsgruppe in der österreichischen Bundeshauptstadt Wien. Die Daten wurden durch semi-strukturierte Interviews mit Eltern generiert, die einige oder alle Impfungen für ihr(e) Kind(er) verweigert haben. Zudem wurden Interviews mit zwei impfkritischen Ärzten, einer Impfgegnerin/Aktivistin und im Rahmen einer Fokusgruppensitzung mit Eltern, sowie zwei partizipative Beobachtungen von impfkritischen Informationsveranstaltungen durchgeführt. Diese Daten wurden dann einer semiotischen qualitativen Analyse unterzogen, wobei der Verweigerungshaltung der Eltern acht große Code-Gruppen zugeordnet werden konnten: *Auswirkungen auf das Immunsystem; Impfschaden; Risikoabwägung; ungewisse Wirksamkeit; Hygiene; alternative Konzepte und Werthaltungen; individuelle Verantwortung sowie Macht*. Anhand der Aussagen der ForschungsteilnehmerInnen werden diese Kategorien vorgestellt, untersucht und interpretiert um im ersten Schritt einen Einblick in das Phänomen der Impfverweigerung in diesem spezifischen Kontext zu erlangen und im zweiten Schritt mögliche Schlussfolgerungen für die klinische Praxis sowie öffentliche Policy zu ziehen.

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I.

INTRODUCTION

Why, by their own account, are individual parents refusing vaccinations on the part of their children? This problem-oriented, medical-anthropological study examines this question within the particular local context of the city of Vienna, Austria, using ethnographic methods of data collection and analysis to identify concepts and experiences relevant to parental vaccination refusal. The medical practice of vaccination has been surrounded by controversy since its invention in the 19th century (Blume 2006, Spier 2002, Poland & Jacobson 2001), and vaccination refusal, in turn, has become a public health issue of global relevance, with major implications for disease control and prevention (Callréus 2010, Streefland et al 1999, Gangarosa et al 1998). In Europe, the goal of measles elimination has proved particularly difficult to achieve, at least in part because of active refusal of vaccines (Hanratty et al 2000), and measles outbreaks have taken place across the continent over the past decade, including several instances in Austria and the surrounding region (Schmid et al 2008, Richard & Massery Spicher 2007, Bernard et al 2007). This study's aim is to explore an issue of global significance within a specific, locally-situated context, as seen from the perspective of refusing parents themselves.

To briefly summarize the contents of this report: this introduction (Chapter 1) will provide theoretical, historical, and regional background information relevant to this project. Chapter 2 will give a detailed description of the research design, including data collection and analysis methods. Chapter 3 will present the study results, focusing on specific aspects of vaccination refusal as described by research participants. Chapter 4 then brings these various aspects of vaccination refusal together in order to identify key issues relevant to parental vaccination refusal in this (and potentially other) contexts.

Theoretical background

The approach to vaccination refusal taken in this study is based primarily upon two major social scientific examinations of vaccination. The first is a series of studies conducted by medical anthropologist and sociologist Pieter Streefland in the context of the *Social Science*

and Immunization Project (*SSIM*); the second consists of a collection of studies presented in the book "*Vaccine Anxieties: Global Science, Child Health and Society*" by social anthropologists Melissa Leach and James Fairhead (2007). These two collections of studies, though different in focus, together provide a theoretical/methodological framework from which to approach this particular research question.

The *SSIM Project* studies provide particular guidance in relation to the nature of vaccination refusal and acceptance. This project, initiated in 1994 and funded by the governments of Denmark and the Netherlands alongside several universities and private institutions¹, involved both national and transnational studies focusing on issues of vaccination in diverse contexts in Asia, Africa, Europe and the United States, with the intention to "improve coverage and sustainability of vaccination programmes by way of a better understanding of their social and cultural aspects" (Streefland 2001:161). Streefland coined the frequently-cited term "local vaccination cultures", which he describes to be defined by the "shared notions [which] emerge when relatives or neighbors exchange accounts of their vaccination experiences...which then colour their subsequent experiences", together with "beliefs about disease aetiology, ideas about the potency and efficacy of modern medicine, and views on the need for preventative health measures" (Streefland et al 1999:1707). It is these "local cultures", he argues, that provide the key to understanding issues of vaccination acceptance and non-acceptance in any given context.

A major conclusion of the *SSIM* studies was that vaccination acceptance is spectrum-like. Streefland and colleagues emphasize that acceptance and non-acceptance of vaccination are far from mutually exclusive, and must be seen in terms of subtle gradation rather than categorical acceptance or refusal (Streefland et al 1999:1710). Their analysis distinguishes three distinct but interrelated modes of non-acceptance. The first mode, which I will refer to in this text as *barrier-related non-acceptance*, is characterized by external factors which have little to do with individual agency, such as issues of insufficient transportation, high costs, or other barriers to access. The second mode, which I will refer to as *experience-based refusal*, is characterized by active refusal of vaccines owing to dissatisfaction with vaccination services, which can stem from (for example) poor organization, rude treatment by health care providers, or the experience of side-effects (real or perceived) after vaccination; individuals refuse to make use of the vaccine-services on offer on the basis of previous experience. The third mode, *concept-based refusal* (again, my title), is also characterized by active individual

¹ Specifically, the *SSIM* project was funded by Ministry of Foreign Affairs of Denmark, the Ministry of Foreign Affairs of The Netherlands, the University of Amsterdam, the University of Iowa, the Royal Tropical Institute (Amsterdam), and the Rockefeller Foundation (Streefland et al 1999:1706).

agency; but, rather than focusing on specific experiences, instead the safety of, need for, or efficacy of specific vaccines and/or vaccination generally is called into question. This mode of non-acceptance can range from instances of individual refusal to group resistance to vaccination programs (Streefland et al 1999:1710). These insights will provide a framework from which to approach aspects of the research design, specifically participant selection and the design of the interview guide to be described in the coming chapter.

Leach and Fairhead also present the results of several anthropological studies carried out in diverse settings, primarily in the United Kingdom and western Africa. Rather than examining the act of vaccination acceptance or refusal specifically, these studies focus on the nature of vaccine "anxieties" experienced by parents both compliant and non-compliant, while incorporating a post-structuralist emphasis on the interaction between individual agency and larger societal structures. They argue that the 19th century development and institutionalization of vaccination, the goal of which was the maintenance of population-level health through the establishment of herd immunity², provides a signature example of Michel Foucault's concept of biopower³. Today, vaccination as public health policy has become entrenched through global vaccination "technocracies": complex networks of technologies, actors, practices and structures (medical, economic and regulatory) that together promote the timely delivery and uptake of vaccination regimens, with the goal of maintaining herd immunity and, in effect, population-level health (Leach & Fairhead 2007:7-9).

It is far from surprising, Leach and Fairhead argue, that these vast systems of vaccine production and delivery may, on the final leg of their journey, fail to connect with a particular

2 In the case of certain types of communicable disease, high rates of vaccination coverage within a population have been shown to significantly reduce the rate of disease transmission, thus providing protection to the population generally, including unvaccinated and/or non-immune individuals; this phenomenon has come to be known as *herd immunity*. Ultimately, robust herd immunity can result in the world-wide disappearance, or *eradication*, of a disease, as demonstrated by small pox (Heymann & Aylward 2006:1-3). Only disease organisms whose lifecycle depends on human hosts are currently realistic targets for eradication: this includes diseases such as polio and measles (Aylward et al 2000), and excludes for example tetanus, which lives in soil (Hinman 1999), and tick-borne encephalitis, which is carried by ticks (Lindquist & Vapalahti 2008).

3 According to this concept, the 19th Century state apparatus began to shift its focus from maintenance of state power through sovereign control of the individual through discipline, to regulation of "the population". Rather than enacting power primarily through the threat of punishment (and death) directed towards individuals, the state began to redirect its energies towards the promotion of life in the form of a healthy population; this new, abstract concept would ultimately come to supersede the individual as the primary field of state intervention. Rather than directly controlling individuals, governments came to focus on the control of standards and norms (with the aim to optimize life, in terms of statistics) through regulation; the disciplining of individual bodies was to be relegated to institutions such as prisons, schools, hospitals, and the nuclear family (the later three all playing key roles in the implementation of state vaccination policies). As Foucault describes it, this shift in the focus of state power to the level of population is expressed through a new emphasis on statistical concepts such as birth rates, mortality and life expectancy- and, in the context of vaccination, herd immunity. By focusing on the population as a field of intervention and regulation, the state promotes its own interest through the creation of a healthy, productive workforce, as well as an effective standing army (Foucault 1992).

child. "Vaccines are...special in linking the most global with the most local and personal. Aiming to reach every child on the planet, vaccination technology has a unique global character. Vaccines are produced, distributed and monitored within systems that are equally globalized. Yet vaccination reaches from the global into the most intimate world of parenting and care. At the needle point, the most global meets the most personal of worlds" (2007:2). Seen in this light, vaccination refusal must be examined both in its unique, highly contextualized, local manifestations, as well as in the scope of a broader global context, what anthropologists Jean and Jean Comaroff have referred to as anthropology on an "awkward scale", an endeavor "of multiple dimensions, that seeks to explain the manner in which the local and the translocal construct each other, producing at once differences and sameness, conjuncture and disjuncture" (2003:147). These insights provide an important contextual framework within which to understand parental agency and the various forces with which parents are made to interact through engagement with health decisions such as vaccination, to be addressed in more detail in the coming pages of this introduction.

Historical and regional context

When parents refuse vaccination on the part of their child, their action is linked to factors both highly local and radiantly global in nature. The following section is meant to contextualize vaccination refusal, beginning with an historical glimpse of the development and institutionalization of the technology of vaccination, which has developed in concert with national and global public health regimes to create a vast system spanning localities worldwide and inspiring a multitude of controversies. The globalization of vaccination in the form of vast "technocracies" (Leach & Fairhead 2007:7) in turn serves as a medium in which regional and national structures of vaccination delivery are embedded, as demonstrated by vaccination policy in Austria.

The invention of the first "vaccine"⁴ against smallpox at the end of the 18th century paved the way for vaccination as medical practice to become a key element of state-lead interventions in the new realm of public health. Initial experimentation and development was followed by the rapid adoption of the technique across Europe in the early years of the 19th century (Spier 2002:80). As mass vaccination campaigns became more common, and

4 The term *vaccination* is derived from the word root *vacca*, or cow, referring to the innovation of using immunogenic material derived from cowpox (a bovine form of smallpox, mostly harmless to humans) to induce immunity to smallpox (Lund et al 2005:203). The invention of the first such "vaccine" is generally attributed to the British physician Edward Jenner, who experimented with the technique in the 1790s and published the results of his experiments in 1799 (Spier 2002:80).

smallpox rates began to decrease more rapidly than expected (for example, smallpox rates in Sweden decreased a hundred-fold within a short time after implementation of mass-vaccination measures), it became clear that mass vaccination not only confers immunity to the vaccinated individual, but also protects non-immune persons through the reduction of the overall net-rate of disease transmission, what has come to be known as *herd immunity* (Heymann & Aylward 2006:2-3). Establishing herd immunity to smallpox at the population level became a national project in states worldwide.

Over the course of the 19th Century, vaccine technologies thrived under the patronage of various governments and colonial regimes. Mandatory vaccination policies were established by a number governments in Europe (Grabenstein & Nevin 2006:31), as well as in the United States, Russia, and Egypt (Lombard et al 2007:31). Mass-vaccination campaigns, often forcefully implemented under the aegis of the military, also spread to the colonies, becoming a common feature of colonial medicine in Africa and Asia (Leach & Fairhead 2007:8). State demand for vaccines themselves would grow alongside what today has become a multinational pharmaceutical industry; of 2010's five top-ranking vaccine producers⁵, three were founded in the 19th Century, including Pfizer (founded in Boston in 1849⁶), Novartis (originally Geigy, Ciba and Sandoz, founded in Switzerland in 1758, 1859 and 1886, respectively⁷), and GlaxoSmithKline (with 19th Century roots in both the US and UK⁸), and, over the course of the century, new vaccines would be developed against rabies, typhoid, cholera, and plague (Plotkin & Plotkin 2008:4).

Structures of vaccination regulation and delivery continued to evolve during the course of the 20th century, alongside the concept of globalized responsibility for human health extending beyond the colonial regime. The early-century predecessors to the World Health Organization⁹ each made efforts to emphasize the borderless nature of public health, establishing the need for preventative and social (as opposed to curative) medicine on a global scale (Balinska 2004:36). This effort culminated with the establishment of WHO as a primary and centralized global health authority, under the leadership of the newly established United Nations, in 1948 (WHO 2007:4).

5 Based on Reuter's 2012 ranking according to global prescription drug sales: 1) Pfizer, 2) Novartis, 3) Sanofi-Aventis, 4) GlaxoSmithKline, and 5) AstraZeneca

<http://www.reuters.com/article/2010/03/26/pharmaceutical-mergers-idUSN2612865020100326>, accessed 10.12.2012

6 http://www.pfizer.com/about/history/1849_1899.jsp, accessed 10.12.2012

7 <http://www.novartis.com/about-novartis/company-history/index.shtml>, accessed 10.12.2012

8 <http://www.gsk.com/about-us/our-history.html>, accessed 10.12.2012.

9 These include the Pan American Health Organization (the first international health authority, founded in 1902), followed by the globally-leaning Office International d'Hygiène Publique (based in Paris), and the League of Nations Health Organization, which was replaced by WHO (Balinska 2004:36).

WHO proceeded to promote new developments in vaccinology¹⁰ on a global scale, paving the way for global vaccination programs and technocratic structures. Starting in 1967, WHO spearheaded a global campaign against smallpox with vaccination as its primary means of prevention, resulting in the world-wide eradication of the disease in 1979, which the organization cites as among its “proudest achievements” (WHO 2007:5). With the success of the smallpox campaign still eminent, WHO established the Expanded Programme on Immunization (EPI) in 1974, resulting in the further coordination of national and regional vaccination programs under WHO's leadership (Streefland et al 1999:1705). All these developments have resulted in the globalization of medical practices in relation to vaccination, connecting a broad network of international, state and regional authorities towards the epidemiological, population-level goals of disease reduction and (when possible¹¹) eradication through the establishment of herd immunity, mirroring the national vaccination projects of the previous century.

Federal vaccination policies in Austria are themselves embedded within these global historical processes and technocratic structures. One of the first public vaccination programs in continental Europe was initiated just south of Vienna in Brunn am Gebirge in 1800 (Moser & Patzak 2008:6), and in 1836 vaccination against smallpox became legally mandatory for all citizens of the Habsburg empire (Mutz 2010:14). After World War II, the newly formed Austrian Republic reestablished compulsory vaccination, making the smallpox vaccine legally mandatory for children under one year; this law was then repealed in 1980 after WHO announced the world-wide eradication of the disease and use of the smallpox vaccine was discontinued (Mutz & Spork 2007:2). Since that time no further compulsory measures have been put into place (Mutz 2010:16).

Also since that time, with the aim of improving various public health statistics including childhood vaccination rates, the Austrian Ministry of Health (*Bundesministerium für Gesundheit*) has attempted to encourage vaccination through a combination of systems and incentives. In 1973, for example, as WHO's Expanded Programme on Immunization was getting underway (Streefland et al 1999:1705), the Ministry introduced the *Mutter-Kind-Pass* (mother-child-health certificate) as a means of encouraging women to attend prenatal appointments and to bring their infants to regular check-ups. The pass included the first official

10 Vaccines targeting seven new diseases were developed between the world wars, including tuberculosis, diphtheria and tetanus; but the “golden age” of vaccinology began in 1949 with the development of techniques to propagate viruses in stationary cell cultures. Since that breakthrough, the number of vaccine-preventable diseases has more than doubled, and many already existing vaccines have been improved upon or reinvented (Plotkin & Plotkin 2008:5-7).

11 See Footnote 2, page 6.

childhood vaccine recommendations, which at that time consisted of three vaccines, the combined diphtheria-pertussis-tetanus vaccine and single vaccines against polio and measles (Mutz & Spork 2007:95). Today, the *Mutter-Kind-Pass* has become a central feature of the Austrian vaccination delivery system, serving as a record of attendance of prenatal and well-child appointments, which are in turn linked to financial incentives in the form of child care payments (*Kinderbetreuungsgeld*) for which every family covered by social insurance in Austria is eligible¹². Through these visits, which are normally carried out by an independently practicing pediatrician or general practitioner, the vaccination status of individual children can be monitored, parents can be reminded of upcoming or missed vaccinations by "well trained clinic staff", and parents who are uncertain about vaccinating their children can be counseled by the pediatrician him or herself (Moser 1998:204).

This positive, universal system of linking financial incentives to well-child visits (Hemenway 1995:137) is coupled with active financing of certain vaccines on the part of the Ministry of Health. In 1997, the ministry gave official recognition to the importance of vaccination by devoting a combination of federal, state and social health insurance funds towards the purchase of childhood vaccines, in effect making select childhood vaccinations cost-free for all children covered by social insurance (Hofmarcher & Rack 2001:57). According to recent statistics, the Austrian social insurance system currently covers 99% of the population (Bundesministerium für Gesundheit 2010:10), making access to free-of-charge childhood vaccinations at least in theory nearly universal. In this way, childhood vaccinations are made accessible to the majority of the population, using the clinics of individual pediatricians as primary¹³ means of delivery and the *Mutter-Kind-Pass* system as financial incentive, creating an environment which in theory should reduce barriers to vaccination while also allowing parents a large degree of autonomy in relations to the decision to vaccinate, alongside access to professional support.

The system determining state-endorsed vaccination recommendations is also embedded within regional (specifically European Union) and global technocratic structures¹⁴. The

12 <https://www.help.gv.at/Portal.Node/hlpd/public/content/8/Seite.080610.html>, accessed 27.10.2012 – it is important to note that payment of *Kinderbetreuungsgeld* is not linked to vaccination; parents who fail to vaccinate their children (but do bring them in for all appointments) still receive payment.

13 As opposed to the United Kingdom or Scandinavia, where the majority of childhood vaccinations are delivered via neighborhood well-child clinics (Stronegger & Freidl 2009:354), childhood vaccination delivery in Austria is organized by the federal district, with some variation. In Vienna, a child can be vaccinated by any doctor who is integrated into the vaccination system (this includes most pediatricians and some general practitioners); routine vaccinations are also available at the 22 Viennese parent counseling centers (*Elternberatungsstellen*), and several other locations: see <http://www.wien.gv.at/gesundheit/beratung-vorsorge/impfen/gratisimpfung.html>, accessed 11.12.2012.

14 The following description is based on a personal interview with an official at the Austrian Agency for Health and Food Safety (*Österreichische Agentur für Gesundheit und Ernährungssicherheit*, or *AGES*), conducted

Vaccine Commission of the Federal Advisory Committee on Health (*Impfausschuss des Obersten Sanitätsrates*)¹⁵, a voluntary panel of experts from medicine and public health appointed by the Minister of Health, is responsible for designing the Austrian vaccination schedule (*Impfplan*) in coordination with guidelines as established by the European Centre for Disease Prevention and Control¹⁶ and the World Health Organization. This schedule, which is in turn published on the Ministry of Health website as well as in relevant medical journals, serves as a guide for doctors in implementing vaccination in their own practices¹⁷. In this way, Austrian vaccination policy merges global public health goals and technocratic systems with its own structures of public health intervention, resulting in a system meant to enable parental compliance with a federally determined but globally influenced vaccination schedule.

Vaccination refusal in Austria

According to the literature, what factors can be expected to contribute to vaccine refusal within this particular context? Like any public health system, the Austrian vaccination system is far from barrier-free, and several studies have connected vaccination non-acceptance to potential access-related factors rather than active refusal. One study commissioned by the Viennese Public Health Department (*Gesundheitsamt der Stadt Wien/MA 15*), in which 1,190 parents in Vienna were interviewed about the vaccination status of their children, indicated that vaccine non-acceptance was primarily associated with low education status and poor German skills as well as large family size (SORA 2003:68-69). A 2009 study of schoolchildren in the district of Styria produced similar results, linking large family size and low education levels to non-acceptance (Stronegger & Freidl 2009:354). One recent study,

on July 22nd, 2010.

15 Since the time of research, the *Impfausschuss*, or Vaccine Commission, has been replaced by the *Nationale Impfgremium*, or National Vaccine Council. This structural change included some alterations in personnel; however, the new National Vaccine Council fulfills similar duties as its predecessor. From personal communication, Austrian Agency for Health and Food Safety, October 8th 2013.

16 Founded in 2005, the ECDC coordinates disease prevention and control policy at the European level, including vaccination policy: <http://www.ecdc.europa.eu/en/aboutus/Mission/Pages/Mission.aspx>, accessed 28.11.2012.

17 The Health Ministry, however, then determines which of the recommended vaccines will be publicly funded, based primarily upon in-house cost-benefit analysis and budgetary considerations. This has resulted in a sort of two-tiered system, in which the state officially recommends a particular vaccination schedule through the Vaccine Commission, but only provides public financing for particular vaccines on that schedule. For instance, at the time of data collection in 2010, the vaccine recommendations for children up to the age of six included the 6-component vaccine (covering diphtheria, tetanus, pertussis, poliomyelitis, haemophilus influenza B and hepatitis B), the combined measles-mumps-rubella vaccine, as well as single vaccines against rotavirus, pneumococcus, meningococcus, hepatitis A, tick-borne encephalitis, and variacella (chickenpox). However, only the two combination vaccines and the rotavirus vaccine were financed by the state; the rest were to be paid for by individual parents. For the complete 2010 vaccine schedule, see <http://www.centralapo.at/impfplan10.pdf> (accessed 29.7.2013).

however, has indicated that active parental refusal may also constitute a significant phenomenon in this context, especially among the well-educated. The *Vienna Vaccine Safety Initiative* (VIVI) conducted a study in 2008 and 2009 interviewing 1,101 parents of children enrolled in city-run kindergartens, titled "Perceptions of Vaccine Safety among Parents and Guardians of Children and Adolescents in Vienna, Austria", with the intention of "closing the gap" on the topic of vaccine safety as viewed by parents, both compliant and non-compliant¹⁸. Only 1% of respondents reported refusal of all vaccines¹⁹; however, 45.7% of respondents reported having actively refused one vaccine or more²⁰, with better educated parents reported to be "among the most critical towards immunization"²¹.

When asked about the basis for vaccine refusal among parents in Austria, Dr. N²², a vaccination expert at the Medical University of Vienna, cited safety concerns characterized by primarily irrational fears of vaccine side-effects. "It's a problem of false risk assessment, [which is] intensified by the fact that as epidemic pressure sinks, the intervals between outbreaks increase. The disease retreats, the vaccination rates rise, and the severity of the disease itself is no longer in people's consciousness. And then there are the side-effects." A similar statement was made in a 2009 article in the *Standard* (a widely-read and respected Austrian newspaper): "effective vaccines dig their own grave – the repression of diseases seems to give possible side-effects more meaning"²³. Otherwise known as the "epidemiological transition", this widely-cited phenomenon causes parent's fears to shift from (no longer prevalent) diseases to the vaccines themselves; the less present the diseases are, the more worrisome vaccine side-effects become. Such risk-aversion is referenced again and again, not only in the local public health and medical literature (Haditsch 2010; Mutz 2010; Maurer 2008; Hrabcik 2007), but also in the international literature on vaccination (for example, Jacobson, Targonski & Poland 2007; Wroe et al 2005; Balinska 2004; Spier 2002; Poland & Jacobson 2001).

On the other hand, there is a strong association between anthroposophic sub-communities and vaccine refusal. The anthroposophy movement is based upon the teaching of Rudolph

18 Although the study results have not yet been published, preliminary findings have been posted on the VIVI website: <http://vi-vi.mobi/project/vaccine-safety-survey-for-parents> (accessed 29.7.2013).

19 This is in line with previous research, which has estimated that 1-2% of parents in Austria categorically reject vaccines for their children (SORA 2003:68; Moser 1998:204).

20 This figure is taken from the summary of Stefan Fitzinger's unpublished 2010 master's thesis available on the VIVI website: <http://vi-vi.mobi/publications/2012> (accessed 29.7.2013).

21 This quote is taken from the summary of Jeong Yun's 2010 unpublished master's thesis available on the VIVI website: <http://vi-vi.mobi/publications/2012> (accessed 29.7.2013).

22 "Dr. N", like all other primary sources referenced in this report, has been anonymized. From personal interview, April 19th, 2012.

23 <http://derstandard.at/1240297915577/Schutzimpfungswoche-Angst-vor-Impf-Nebenwirkungen>, accessed 11.12.2012.

Steiner, a turn-of-the-century Austrian philosopher who claimed that certain febrile illnesses, including measles, were linked to a child's spiritual development (Hanratty et al 2000:378), thus problematizing the desirability of disease-avoidance through vaccination. In 2008 a measles outbreak reaching from Austria to Germany and Norway was traced to an anthroposophic school and daycare in the Austrian city of Salzburg, where the majority of the students were unvaccinated (Schmid et al 2008); a similar outbreak in the federal province of Styria the following year was also linked to an anthroposophic school (Kasper et al 2009). This association of vaccination refusal with alternative beliefs and lifestyles has been demonstrated in the surrounding region; an eight-month long outbreak in Switzerland, from November 2006 to July 2007, was linked to an anthroposophic boarding school and involved many children and teenagers of parents who didn't wish to vaccinate (Richard & Spicher 2007), and a similar outbreak in Bavaria was traced to unvaccinated pupils at a Montessori school, where "skeptical attitudes" towards vaccination were common (Bernard et al 2007)²⁴.

Dr. N distinguishes between anthroposophic objectors, whose alternative worldview put them in the same category as those who refuse vaccination on religious grounds, and "...how should I put it, the intellectually neglectful...with enough of an education that one would think that they could have informed themselves to the point that they'd know better. They say yes, the child has to go through [the disease experience], homeopathic treatments will be used, and so on. There are also it seems scientists that fall into this category, who research virus receptors at a scientific institute, and then give their child *globuli*²⁵ to swallow in the evening. Terrible."

Complimentary healthcare, in particular homeopathy, is indeed also associated with vaccine skepticism, both in this and other contexts. According to the Vienna Vaccine Safety Initiative survey, better educated, vaccine-critical parents are also more likely to make use of complimentary medical services generally²⁶, and researchers in other contexts have shown a correlation between complementary medical care and vaccination refusal, from Washington State and Massachusetts in the USA (Downey et al 2010) to European contexts, including Austria (Ernst 2002). A 1994 survey which attempted to contact all registered homeopathic doctors in Austria (of 230, 117 responded) indicated significant skepticism in relation to vaccination: for example, only 28% considered vaccination to be an important measure for

24 Hanratty and colleagues who have examined similar outbreaks in the United Kingdom speculate that the existence of these communities, with their concentration of un- or under-immunized individuals, might permanently jeopardize the goal of measles elimination in Europe (Hanratty et al 2000).

25 Small white pellets which serve as the primary delivery medium for homeopathic treatments.

26 This quote and information is taken from the summary of Jeong Yun's 2010 unpublished master's thesis available on the VIVI website: <http://vi-vi.mobi/publications/2012> (accessed 29.7.2013).

disease prevention (Rásky et al 1994). Today, the Austrian Society for Homeopathic Medicine (*Österreichische Gesellschaft für Homöopathische Medizin*, or ÖGHM) features a statement about vaccination prominently on its website; the statement carefully concedes the importance of vaccination as a public health measure, while emphasizing a parent's autonomy in relation to health decisions affecting their child, as well as uncertainty surrounding the effects of vaccines in relation to allergies, autoimmune disease, diabetes, and other *Gesellschafts-krankheiten*, or diseases of civilization.²⁷ Many outspoken vaccine critics in the German speaking world are homeopathically trained, including the pediatrician and classical homeopath Dr. Steffen Rabe, organizer of the vaccine-critical website <http://www.impf-info.de>²⁸ and Dr. Martin Hirte, author of the popular and critical "Handbook for the Individual Vaccination-Decision" (Hirte 2008). Dr. Johann Loibner, a prominent Austrian anti-vaccination activist and homeopathic doctor, was banned from practicing as a physician by the disciplinary commission of the Austrian Medical Association (*Ehrenrat der Österreichischen Ärztekammer*) in 2009 owing to his aggressive and outspoken anti-vaccination stance (Euler 2010:38)²⁹. In Vienna, several homeopathic doctors offer "vaccination counseling", either individually or as group discussions (observational data from two such sessions was included in the data set for this study).

In short, the available literature links active parental refusal of vaccines in this particular context to relatively mainstream safety concerns on the one hand, and on the other to sub-communities characterized by alternative beliefs. Somewhere in the middle certain parents, often well-educated and/or with a tendency towards the use of complimentary medicine, are displaying a potentially significant degree of vaccine-skepticism. It is this particular group who will be the target of this study, with the aim of ascertaining why these parents, within this particular context and from their own perspective, are in some cases motivated to refuse vaccines on the part of their children.

27 <http://www.homoeopathie.at/oeghm-statement-zum-thema-impfen/>, accessed 21.11.2012

28 <http://www.homoeopathisches-aerztehaus.de/index.php/dr-steffen-rabe>, accessed 30.4.2013

29 Since the time of writing, Dr. Loibner's case has been reviewed by the Austrian Supreme Administrative Court (*Verwaltungsgerichtshof*). The Court chose to restore Loibner's right to practice on the grounds that the Medical Association and other involved bodies had failed to adequately justify their assessment (See <http://derstandard.at/1376534810961/Hoehchstgericht-rehabilitiert-impfkritischen-Arzt> , accessed 25.9.2013).

II.

PROJECT DESIGN and METHODS

By their own account, why are individual parents in a particular local context refusing vaccination for their children? A selection of ethnographic methods were utilized to investigate this exploratory, problem-oriented research question. Ethnography has been described as "a special methodology that suggests we learn about people's lives (or aspects of their lives) from their own perspective and from within the context of their own lived experience" (O'Reilly 2005:84); its methods are particularly well-suited to the emic exploration of "locally specific meanings and behaviors", such as those surrounding vaccination refusal, in order to inductively and/or recursively build "theories of cultures- or explanations of how people think, believe and behave- that are situated in local time and place" (LeCompte & Schensul 1999(a):1-15). The focus of this study on the emic understandings and experiences of parents within a particular social context is very much in line with the ethnographic project, making ethnographic methods particularly suitable for its implementation.

One of the hallmarks of ethnographic research is the foregrounding of the researcher him or herself as a primary tool of data collection. "The ethnographer's principle database is amassed in the course of human interaction," thus "the personal characteristics and activities of researchers as human beings and as scientists become salient in ways not applicable to research where the investigator maintains more distance from the people and phenomenon under study" (LeCompte & Schensul 1999(a):xiv). It is thus necessary that I situate myself as researcher within the context of this particular study. As a Viennese resident and parent myself, I shared much in common with interview participants in terms of everyday life; in fact, it was observations from within my own social circle in Vienna that initially introduced me to the topic of vaccine refusal, and that same circle was to provide a basis from which to begin participant selection through the use of *convenience* and *chain referral selection* methods, to be described in detail in the following section. This familiarity was complimented by my role as an outsider (I am a U.S. American and non-native German speaker) as well as my status as a vaccine-compliant parent (both my children are fully vaccinated), allowing for a balance of familiarity and foreignness particularly suited to ethnographic research. It is possible that certain participants under-emphasized critical judgments towards vaccine-compliant parents for my benefit, and that the strong emphasis placed by most participants on

the "personal nature" of the vaccination decision, as presented in Chapter 3.5, is in part a result of this relational aspect; however, the existence of a strong thematic of parental autonomy and individualism in other areas (to be discussed in Chapter 4) indicates that relational considerations may have influenced the degree of emphasis, but not necessarily the nature, of this particular discussion.

Another hallmark of ethnographic research is the use of mixed methods and multiple data sources to access a variety of sources relevant to the research question (LeCompte & Schensul 1999(a):9). Targeted discussion with vaccine-refusing parents (specifically *semi-structured interview* and *focus-group discussion*, to be discussed later in the chapter) was determined to provide the most direct access to data relevant to the research question, and was thus selected as the primary means of data collection; however, as research progressed, important sources of vaccine-critical information and advice were spoken of by focus-group and interview participants. A few particularly prominent resources (specifically two local vaccine-critical doctors and events they organized, as well as a specific anti-vaccination activist organization) were thus selected for incorporation into the data set using a combination of interview and participant-observation techniques, to be discussed in detail in the coming pages.

Traditionally, the anthropological/ethnographic approach has relied on site-based participant observation (as well as reified cultural definitions) to locate a study; in today's globalizing/globalized world, however, many ethnographies examine groups that are embedded, or even hidden, within larger communities, and current cultural concepts question whether truly bounded, internally consistent cultural "groups" exist, or indeed ever existed (LeCompte & Schensul 1999(a):110). This study, by focusing on a specific problem and utilizing targeted discussion as a primary means of data collection, lacks a traditional research "site" and does not focus on a cultural or otherwise predefined "group". Instead, through the use of *chain referral selection* to be described in the coming pages, participants are allowed to emically determine their own "locality" according to their own social connections and ties. This provides an alternative method for "grounding" the research in a particular local context, in accordance with Pieter Streefland's concept of "local vaccination cultures", which posits that shared notions about vaccination arise through social exchange (Streefland et al 1999).

Participant selection

After the selection of targeted discussion as the primary means of data collection, the next step to establishing a research design was to develop criteria for interview and focus-group

participation. The research question targets vaccine-refusing parents as the study's focus population; *criterion-based selection* was used to determine eligibility for participation (LeCompte & Schensul 1999(a):110-124). As discussed in the previous chapter, anthropological examinations of vaccination non-acceptance have shown that acceptance and refusal are not distinct phenomena, but instead form a behavioral spectrum (Fairhead et al 2006; Streefland et al 1999); in keeping with this finding and with the exploratory nature of this study, minimal participation criteria were set in order to allow for the inclusion of a broad range of non-acceptance behaviors, while at the same time limiting its scope in order to focus on the segment of non-acceptance characterized by active agency, defined in this study as "refusal".

In order to qualify for participation, a person had to have:

- a) refused *at least one* of the (at the time) publicly-financed childhood vaccinations³⁰
- b) for *at least one* of their children.

The breadth of these criteria focus on the *act* of rejecting one or more vaccines rather than on the categorical rejection of vaccination as a general practice; such an act does not necessarily exclude the possibility of vaccination at a later time, allowing for a variety of parental approaches and perspectives to be included in the data set. These criteria do however exclude fully compliant parents, and, by limiting refusal to publicly funded vaccines, they will also tend to exclude parents who are generally willing to vaccinate their children but are hesitant, for whatever reason, to pay for vaccinations, a potentially large group. Insurance coverage was not, however, included in the participation criteria, and participants were explicitly asked if insurance issues or other practical or barrier-associated factors were relevant to their decision in order to allow for the possibility that factors distinct from parental agency are contributing to vaccine refusal.

Study participants were then identified using a combination of *convenience* and *chain-referral selection* strategies. *Convenience selection* was chosen to establish initial contact with potential participants, utilizing the social network of the researcher (myself) as a point of access. This technique, in which participants are selected based on their accessibility to the researcher, is not particularly rigorous, but is considered appropriate under some circumstances, especially for exploratory research (Schensul & LeCompte 1999:235) as well

³⁰ In 2010, these included: 1) the rotavirus vaccine, 2) the 6-component vaccine against diphtheria, tetanus, pertussis, poliomyelitis, haemophilus influenza B, and hepatitis B, and 3) the *measles-mumps-rubella* combined vaccine. For details see <http://www.centralapo.at/impfplan10.pdf> (accessed 29.7.2013). These particular vaccines are available free of charge to the majority of Austrian residents: see page 10 of this report for details.

as student research (O'Reilly 2005:85). In this particular case, I used my own social network as a convenient starting point for the location of participants for the first step of research, in this case an exploratory focus-group session (to be discussed in more detail later in this chapter). In order to identify initial focus-group participants, an open invitation was sent out per email to a list of 38 acquaintances; this list included all members of a local daycare-cooperative as well as several other parent's groups active in Vienna in which I myself participate. The email generated significant interest; of the many who replied, those who fit the participation criteria were recruited for the focus-group.

Interview participants were then identified using *chain referral selection*. According to this technique, each study participant is asked by the researcher to suggest other potential participants, using pre-existing social networks to move further away from the initial point of contact as the study progresses (Schensul & LeCompte 1999:241). This method is considered appropriate for small-scale, exploratory studies such as this one, and has indeed been used in many qualitative studies in order to gain access to specific, hard to reach populations (Atkinson & Flint 2001) as well as in studies exploring issues surrounding vaccination acceptance and refusal (see for example Cassell et al 2006; McClelland & Liamputtong 2006; Salazar et al 2005). In practice, focus-group participants as well as subsequent interview participants were asked to recommend other parents for interview participation; these parents were then contacted to verify eligibility and arrange interviews.

Data collection methods

A combination of ethnographic/qualitative methods were used for data collection. The most prominent of these was *semi-structured interview*, with supplemental use of *focus-group discussion* as well as *participant observation* techniques, all of which were used to generate semiotic data in the form of transcripts and observational protocols.

A *focus-group discussion* was selected as a means of initial exploration of vaccination refusal in this particular context. Focus-groups are widely used as a method for quickly generating a range of experiences, views and/or responses on a particular topic, while at the same time emphasizing "the idea that people's feelings, perception and attitudes are formed not in isolation, but in interaction with others" (O'Reilly 2005:113). The focus-group session, titled "reasons not to vaccinate children" (*Gründe, Kinder nicht zu impfen*) took place at my home with myself as mediator and was conducted with the help of a prepared guide consisting of open-ended points of discussion exploring ideas about vaccination and vaccination refusal.

Of the group of seven who signed up for the meeting, only 3 actually managed to attend; but despite the small showing, the discussion was lively. The 70-minute session was tape-recorded and transcribed, and the resulting data provided the basis from which the semi-structured interview guide was developed.

As targeted discussions were deemed to provide the most direct access to emic grounds of vaccination refusal, *semi-structured interview* was selected as a primary means of data collection. Semi-structured interviews are particularly well-suited to problem-oriented ethnographic studies. The use of an interview guide with certain fixed elements allows the researcher to target particular topics, allowing for a degree of consistency and comparability between interviews; at the same time the purposefully open-ended nature of interview questions and the allowance for some variation in sequencing creates a large degree of flexibility for both participant and researcher, enabling participants to focus on the matters that are most important to them (O'Reilly 2005:116).

A total of 13 semi-structured interviews were conducted. Ten interviews were done with parents who had refused some or all vaccines for their children (according to the criteria described in the previous section); these interviews were conducted using an interview-guide. On the basis of participant recommendations, two vaccine-critical healthcare practitioners (both with homeopathic training) and one local anti-vaccination activist were also contacted and interviewed using an adapted version of the parental interview guide. The interview site was arranged at the convenience of the particular participant, and interviews ranged in length from 40 to 70 minutes. All interviews were tape-recorded; the ten parental interviews were transcribed in their entirety, while the practitioner and activist interviews were selectively transcribed for inclusion in the data set³¹.

Both interviewed doctors organize vaccine-information events which multiple participants reported attending; aspects of *participant-observational* methods were used in order to include these events in the data set. *Participant-observation* is often characterized as the defining method of ethnographic inquiry; elements of this method, in particular the recording of events relevant to research through the writing of detailed field-notes (Emerson et al 1995), were used in order to expand the data set in a way consistent with participant experiences. I attended both sessions as a parent and researcher, took detailed notes on the interactions I witnessed and took part in, and then used these notes to create participant-observation protocols, focusing on lines of parental inquiry as well as arguments for and against

31 These three interviews were conducted to obtain background information about vaccination controversy and relevant policy in Austria, as well as to explore the local phenomenon of vaccination refusal. Only sections deemed directly relevant to the qualitative analysis were transcribed.

vaccination as presented by both the doctors and parents in attendance at the sessions. These protocols were also included in the final data set.

It should be noted that all research participants have been given appropriate anonymity. Focus-group participants are referred to by number (1-3), and interview participants are referred to by letter; A-J for parental participants, Dr. K and Dr. L for the two medical practitioners, and Mrs. M for the anti-vaccination activist. All research was conducted in German, and transcriptions were also written in their original language; only passages selected for inclusion in the final text were translated into English.

Analysis

Techniques of qualitative analysis, specifically the creation and implementation of a coding system, were selected for the analysis of the resulting body of semiotic data. Qualitative analysis can be executed using a predetermined coding system, or a coding system can be developed through the organization and analysis of the data generated by the specific study; reading and organization of this data into "codes" and code-groups allows for the isolation of items, patterns, and structures, ultimately resulting in the creation of a stable coding system. This is an iterative process in which the developing analytical structures are repeatedly re-evaluated through re-reading and when necessary re-coding of the original data, eventually resulting in a consistent analytical structure for interpretation and evaluation (LeCompte & Schensul 1999(a):150-154). In keeping with this study's emic focus and exploratory nature, the second method was selected, allowing the data itself to generate a coding structure through an iterative analysis, with the aim of uncovering concepts, experiences and explanatory models within the data in order to create a systematic analytical structure for the presentation of results, and ultimately to generate hypotheses relevant to the research question.

In their guide to analyzing ethnographic data, Margaret LeCompte and Jean Schensul describe a specific vocabulary useful for defining discrete analytical elements. These include "item", a discrete and concrete unit of analysis with a corresponding code; "pattern", a collection of items or categories of items that fit together or relate to each other; and "constituent" or "structure", larger groups of patterns or relationships among patterns that point towards theoretical explanations of cultural phenomena (LeCompte & Schensul 1999(b):67-68). Similar analytical units were used for the analysis presented in this report, with some variations in vocabulary which have been adapted to fit the study's semiotic focus.

As used in this study, coded "items" which arise together frequently to form a consistent argument or other form of story constitute a "storyline". Some storylines are consistent enough to be represented by a single code and would therefore be defined as an "item" according to the above definitions, while others arise through the interaction of several items and are therefore roughly analogous to "patterns". These storylines in turn form "code-groups" (equivalent to constituents or structures), which each represent a specific, internally consistent aspect of vaccine refusal.

In practice, after all data had been collected and interview material had been transcribed, the process of qualitative data analysis was begun. An initial reading of the data set resulted in a collection of "open" codes (codes that have not yet been placed in a systematic structure); several rounds of organizing, re-coding and re-organizing resulted in the identification of a number of consistent storylines, which were then organized into eight major code-groups. Data collected from parents participants (both through interviews and focus-group discussion) was allowed to drive this process; any storylines arising in other areas of the data set that were not spoken of by participating parents were excluded from the final analysis, in accordance with the focus of the research question on parental refusal. Once the coding system had been finalized the resulting groups of text were then edited and organized; the results of this process, in which participants discuss in their own words various aspects of vaccine refusal, are presented in the coming chapter.

III.

RESULTS

The following chapter presents the results of data analysis, through which eight major groups of storylines (or code-groups) relevant to parental vaccination refusal were identified. These eight groups are presented here in six sections according to their focus on 1) vaccine safety, 2) vaccine necessity, 3) vaccine efficacy, 4) alternative concepts/values, 5) individual responsibility, and 6) issues of power and influence. Each section describes, through the voices of participants, a specific aspect of vaccination refusal, followed by a brief discussion exploring possible connections to other aspects as well as general relevance. It should be noted that no attempt has been made to evaluate the factual accuracy of participant statements according to normative/scientific standards; instead, these presentations are intended to create a portrait of vaccination refusal according to the understandings of the participants themselves.

The use of convenience and chain-referral selection techniques within this study resulted (predictably) in a relatively homogenous data set. Participants are uniformly urban, overall well-educated and affluent, and all reported full insurance coverage as well as unhindered access to health services where vaccines are provided free-of-charge. In fact, a number of participants reported investing financially in the decision to refuse recommended vaccinations, whether indirectly in the form of supplemental insurance (which would cover visits to alternative, vaccine-critical practitioners), or directly through consultation with alternative practitioners or the purchase of alternative vaccines. It is therefore less than surprising that within this quite specific social context, references to *barrier-related non-acceptance*³² were absent. When asked directly, participants consistently denied any sort of practical factors as relevant to their decision to refuse vaccination. Instead, participant statements and other forms of collected data focused on *conceptual* and *experiential* aspects of non-acceptance, what this report has defined as vaccine refusal.

In order to aid in the reading of this chapter, a table listing both parent-interview and focus-group participants has been included on page 24. The table includes names used (the letters A - J for interview participants, and numbers 1 – 3 for focus-group participants); gender; age,

³² Associated primarily with external circumstances and not necessarily with the will of the parent: see page 5 of this report.

education and profession (only collected from interview participants); and child/children's age and vaccination status at time of interview according to participant reports. These reports indicate a spectrum of vaccination behaviors from refusal of all vaccines to discontinued vaccination to selective vaccination (see table for details). Such behavior is of course distinct from future openness to vaccination; in response to the question "Do you plan to give your child any vaccines in the future?", only two (F and J) responded with a categorical "no". The majority of participants expressed varying degrees of uncertainty about future vaccination plans, and some spoke of plans to give specific vaccines, to be described in more detail in the coming chapter. It should also be mentioned that all participants spoke in interview of a degree of involvement with various forms of complimentary medicine, ranging from general interest to active consultation with alternative practitioners; however, only two participants (again, F and J) claimed to rely exclusively on alternative practitioners for standard care, and most participants reported use of both conventional and alternative medical services.

Several vaccines are featured prominently in the coming pages and therefore warrant a brief introduction here. By far the most frequently spoken-of vaccines were the 6-component vaccine and the FSME vaccine, followed by the MMR and rotavirus vaccines. The 6-component vaccine is currently recommended in Austria as of 3 months of age, and provides protection against diphtheria, tetanus, pertussis, poliomyelitis, haemophilus influenza B and hepatitis B; this vaccine is publicly financed and therefore available free-of-charge to any child covered by Austrian social insurance. The FSME vaccine provides protection against tick-borne encephalitis, which is endemic to certain regions in Austria (Lindquist & Vapalhti 2008); it is not publicly financed at this time, and is recommended as of 1 year of age. The MMR vaccine, which provides protection against measles, mumps and rubella, is also recommended as of one year, while the rotavirus vaccine against certain forms of diarrheal illness is recommended as of seven weeks of age; both are publicly financed. Other vaccines on the 2010 schedule for infants and children are rarely (if ever) referred to explicitly by participants³³.

33 For the complete 2010 schedule, see <http://www.centralapo.at/impfplan10.pdf> (accessed 29.7.2013).

PARTICIPANT DATA

Interview Participants	Age	Gender	Education and Profession	Child(ren)'s age and current vaccination status
Participant A	34	F	Apprenticeship, Cosmetician	3 years, discontinued
Participant B	32	F	Matura ³⁴ , Graphic designer	3 years, selective (tetanus, FSME)
Participant C	33	F	Matura, Administrator	6 months, unvaccinated 2 years, unvaccinated 4 years, discontinued
Participant D	42	F	Matura, Secretary	1.5 years, unvaccinated 6 years, fully vaccinated 16 years, fully vaccinated
Participant E	37	M	Matura (technical), Manager	3 years, selective (tetanus, FSME)
Participant F	40	F	Matura+Acting Conservatory, Actor	2 years, unvaccinated
Participant G	46	F	Matura, Artist/Librarian	5 years, unvaccinated
Participant H	36	M	Magister ³⁵ , Psychologist	3 years, selective (tetanus, pneumococcus) 6 years, fully vaccinated 14 years, fully vaccinated
Participant I	34	F	Matura, Import/Export	2.5 years, discontinued
Participant J	41	M	Discontinued secondary education, Carpenter/self-employed	12 years, unvaccinated

Focus-group Participants	Gender	Child(ren)'s age and current vaccination status
FG Participant 1	F	3 years, unvaccinated
FG Participant 2	F	3 years, selective (tetanus)
FG Participant 3	F	3 years, selective (diphtheria-tetanus, FSME) 8 years, selective (diphtheria-tetanus, FSME)

Notes on vaccination status typology (based on participant reports):

Unvaccinated: Child has not yet been given any vaccinations.

Discontinued: Child's vaccinations were halted mid-regimen (all parents in this data set reported ceasing vaccinations after the first dose of the 6-component vaccine).

Selective: Child has been given specifically selected vaccines.

34 Secondary education in Austria is divided into academic and vocational tracks. The *Matura* is received after the successful completion of the academic-track final exams, and is generally required for entrance to university or other forms of higher education; it is therefore associated with a significant amount of social status (more so than a U.S. American high school diploma, by comparison).

35 A *Magister* is a university degree roughly equivalent to a master's.

Chapter 3.1 Are vaccines safe?

The following section presents participant concerns about the safety of vaccination. Issues of vaccine safety were consistently emphasized by participants, with all but one interview participant (J) citing aspects of vaccine safety as a primary grounds for refusal. Participants expressed a wide variety of concerns which tend to organize themselves around two major features: first, the immune-system (and the possible effects vaccines may have on it), and second, the popular German term *Impfschaden*, which has been translated in this text as vaccine-damage. This distinction has resulted in the identification of two distinct aspects of vaccine-safety concerns; on the one hand, concerns were focused on the potential impact of vaccination on the immune-system, while on the other hand attention was directed towards the possibility of serious vaccine-damage, which was rarely linked by participants to specific understandings of the immune-system and its vulnerabilities. While several participants (especially A, C, D, and G) spoke of both aspects as relevant to their decision to refuse vaccination, a number of participants focused predominantly on only one aspect as relevant, reinforcing the validity of this distinction.

Immune-system concerns

The immune-system was featured in a number of safety-related storylines spoken of by participants. These included the concern that vaccine exposure (especially but not only in relation to combination vaccines) can negatively impact the immune-system; that this can result in the development of allergies or other unknown effects; that age is a significant factor, resulting in the argument for delayed vaccination; and that sickly, fully-vaccinated children provide uncertain evidence of these effects. A number of participants (specifically A, B, E, G, H, and I) cited storylines from this group as central to their refusal.

Participant A, for instance, expressed general concern about the effects of vaccination on the young immune-system. When asked about her primary reason for refusing vaccination, she said:

"I mean, I've heard a lot about vaccine-damage. And then I think, it's also probably not the best for the immune-system, you know? Maybe the child gets something else, an allergy or whatever, that maybe [this aspect] has been researched too little...because I think, a baby, already vaccinated at 2 or 3 months, I just don't know if that's not going to have effects, on how the immune-system develops and

everything."

She found the 6-component vaccine to be particularly problematic in this regard:

"...because it's, wait, 4, 5, no 6 components in one [injection]...I started to wonder if that can really be the best, I mean, a small baby, I mean for the immune-system, if that's good. The doctor explained that it's better than giving them individually, it's done this way these days, all the vaccines in one injection...but for me it was still worrisome."

Participant D spoke of similar concerns:

"Children are pumped full of all these chemicals and things that simply aren't necessary, because I think it just can't be the best thing for the immune-system...I mean, a vaccine with six components, for such a tiny body! Crazy, really, don't you think? It really bothers me, six things at once."

Participant E was particularly concerned about the number of vaccines a small child would be exposed to if vaccinated according to the state recommendations:

"When we saw [the vaccination schedule], I mean, what all is going on there? First month, third, whoa wait a minute, and they're all combination vaccines, or many of them- a child, so many injections, all mixed together at once, practically! I don't know, maybe that's exaggerated, but it's a lot...The amount takes me aback a little, because I do think that could have an effect on the immune-systems of certain children, they're still so small, their immune-system is untrained...maybe later, why not later, why does it have to happen so early? Why already a three month old child?"

When asked about his primary reason for refusing vaccination, he also spoke of the possibility of a negative impact on the immune-system, especially in relation to allergies:

"I just think there's a certain, a certain lack of research, in regards to side-effects...especially with these combination vaccines. Who knows how that's going to effect the body, that it won't have any other influence. And I always have the feeling that then allergies for example, they've also increased in recent years. Or in the last however many years they've increased, and at the same time of course there are so many more vaccines...So that's a reason for me, that I'm just not sure what effects [vaccination] might have. Because you're vaccinating a child who's practically, who's still weak in terms of the immune-system, in principle. And right at the beginning, one packs in such large doses, and the body has to manage all that, to be able to cope with it."

He specifically denied the relevance of vaccine-damage for his refusal, while again pointing towards the possibility of allergies or other side-effects:

"That [my son] really reacts badly, that's not really my fear. Above all because I'm

a numbers person, and from a statistical point of view, it's most likely that exactly nothing will happen to him after a vaccination. So I don't get panicked when he gets an injection, waiting the next day, 'what's happened to him?' No...that's not my fear. But maybe, there could be side-effects, allergies, or something similar, maybe."

Participant H also stated that immune-system concerns were of central importance to him:

"The most important factor is the immunological reaction to vaccination, for example allergies, or the triggering of allergies...in that the immune-system is put under strain in a way that it isn't accustomed to. Because we're not normally, pathogens are not normally taken in intravenously, or intramuscularly, or however, right? Normally they pass through something, our mucous membranes for example, and already at that point the immune-system starts to intervene. And instead, this direct application."

These participants are concerned that vaccine exposure, and especially the exposure to combination vaccines, might overwhelm and possibly damage the immune-system, resulting in allergies or other unknown side-effects.

Age and delayed vaccination

Age was pinpointed by a number of participants as an important factor in relation to vaccination and immune-system effects. Participant G, for example, said that she and her partner, after much debate, had

"...decided, for a combination of reasons, that it's simply irresponsible and dangerous to vaccinate, above all for small children who don't have a fully developed immune-system."

Several participants expressed the view that older children are better able to cope with vaccination. Participant B said that although she is now unsure if she will give her son any vaccines other than FSME and tetanus, she had originally meant only to delay vaccination,

"...so that the immune-system could react better...I mean, I don't know if it has to do with the immune-system directly, or if they're simply stronger [when they're older]. I mean, such a tiny baby, 3 months old, a 6-component vaccine, I don't know...I have the feeling [older children] can handle it better."

Participant C also felt that vaccinating older children is less dangerous than vaccinating babies:

"I think, [when they're older], the immune-system is a bit more mature than it is in a baby, in a little child. Slowly, with a few, with kindergarten, the immune-system strengthens itself a bit, it's like that. And then maybe they can take [vaccination]

better."

The idea that the ability to "cope" with vaccination improves with age was also reported in the form of homeopathic doctor's advice. Participant I said her doctor, a privately practicing homeopath, told her that she could vaccinate:

"...when the child is older. Because by then [the child] will have a stronger immune-system- that's what I was told. That a three month old child, it's still adapting to its environment. It gets new things to eat, and mother's milk if it's still breastfed, everything's constantly changing, it has to get used to all that. And then you pack in a vaccine- that's how it was explained to me."

Participant D also went to a homeopathic doctor for advice:

"He said that often it's bad, because many children are breastfed until three months, that many people think okay, three months, super, I'll ween my baby, and then exactly then at three months they start vaccinating. And that is exactly the worst time, because a child's immune-system needs another three months after weening in order to build itself up, and that many children are vaccinated right at this vulnerable moment."

Both participants were thus advised to delay vaccination in order to allow the immune-system to develop before subjecting it to the strain of vaccination.

Both Dr. K and Dr. L recommend delaying vaccination until after at least the first birthday, which, they argue, allows for both undisturbed development and reduced vaccine exposure³⁶. As Dr. K phrased it:

"For me, in the first year of life, the child's being is still in such need of adaption, is still so immature, also that the immune-system is just beginning to develop, that the nervous-system is just beginning to develop. You can see this in a baby's developing coordination and motor skills...My position is to give the immune-system and the nervous-system room and time to develop, and only intervene with vaccinations later."

Every year that vaccination is delayed, she argued, is time won for this development.

Similarly, Dr. L said one of his primary criticisms of vaccination concerns vaccination timing:

"If I'm going to vaccinate, then I should think about the timing, because in the first year the immune-system is very vulnerable, very open to influence. And, if at that point- many side-effects might relate to early vaccination. A lot of vaccinations can just be given later, if the parents say yes that's what I want, then one can say yes, vaccinate after the first birthday, when the immune-system is

³⁶ On a practical level, delayed vaccination cuts down on the number of booster shots a child will require, and thus the amount of preservatives and other vaccine components that a child is exposed to, according to both doctors.

already much more stable."

He argues that vaccination in combination with a not-yet-fully-developed immune-system has damaging potential. In short, concerns that vaccination may negatively effect the immune-system are linked by many participants to the factor of age, reasoning that the more mature the immune-system is, the better able the child will be to cope with the strain of vaccination.

Allergies and other considerations

A number of participants emphasized the possibility that certain children might be prone to immune-system damage on account of their individual health histories, especially in relation to allergies and other immune-system disorders as well as instances of minor vaccine-reaction (in the form of fever or malaise).

Participants B, H and I linked their refusal to their child's specific health-history, which they believe makes their child particularly vulnerable to vaccine side-effects. Participant B, for example, spoke of a family history of allergies as a primary reason for refusal:

"A real factor was allergies. In our family, my husband has hay fever to the point that it effects his lungs, and I have a severe bee-allergy, and I thought it better to wait with vaccination, so that the immune-system could react better...[originally] the main reason [to refuse vaccination] was these allergies. Because our doctor said, he recommended that with allergies in the family, that one should wait...And I asked, what [vaccines] do I really need in the first two years, because the doctor said okay, it would be good not to vaccinate, so that his immune-system can be trained, and then one can start."

After her son turned two, she had him vaccinated against tetanus and FSME, and is now unsure about continuing with further vaccinations for reasons other than safety (to be discussed in the coming sections).

Participant H also spoke of specific health-concerns as relevant to refusal. His daughter suffers from childhood arthritis, a form of autoimmune disease,

"...and for that reason we're trying to give her as few vaccinations as possible, because autoimmune diseases, this has been established multiple times, can be provoked through vaccination. A least given a push."

Because she was visiting the hospital frequently, his daughter was given single doses of the tetanus and pneumococcus vaccines; once these visits were discontinued, any plans for further vaccinations were abandoned as well, at least for the time being.

Participant I also suffers from allergies, which a homeopathic doctor diagnosed as a

reaction to mercury-containing vaccines; she started to worry that her son might be prone to similar vaccine-reactions after he responded badly to the first dose of the 6-component vaccine.

"He was so out of it, after the vaccination, my hair just stood on end! He didn't get a fever. But you could see it that the child felt unwell, that he wasn't doing well, I mean he looked terrible...I really got scared after he reacted to the vaccine like that."

She decided to discontinue her son's vaccinations after this experience, primarily out of fear that he might be particularly susceptible to developing allergies similar to her own:

"I've had a lot of problems because of vaccines! There are plenty of people, they get the whole lot, and for them it's no problem. But for me it was a problem, a serious problem...and now I have to find a way for my child. And he reacts like this, and I have to take this into account."

For this reason, she chose to discontinue her son's vaccinations, based upon a combination of professional advice and her own estimation of her child's individual ability to cope with vaccination.

There were several other mentions of negative reactions to vaccination as grounds for worry or refusal. A mother at Dr. K's information session, for example, described her son as having reacted badly to the first dose of the 6-component vaccine; he developed an ear infection and a high fever on the evening after the injection. She said that the experience frightened her, and that she had come to the information session in order to find out if it's safe to continue with vaccination. Participant A, who was already uncertain about the safety of vaccines, was also taken aback by her daughter's reaction to the first dose of the 6-component vaccine: "The day after, somehow, she was sort of weepy, and stuff like that, as if she had a slight cold. And I do think that it was from the vaccination." After this experience, Participant A chose to discontinue her daughter's immunizations.

All these participants have previously linked early vaccination to negative immune-system effects; here they emphasize the importance of taking individual health histories into account when considering vaccination, while minor reactions to specific vaccines are taken as warning signs that the individual child might be prone to ill-effects.

Sickliness as a vaccine-effect?

Concerns that vaccination can compromise or weaken immune function were sometimes illustrated through stories of constantly ill, fully-vaccinated children. For example, Focus-

group Participant 1, when asked if "vaccine-damage" was a concern for her, answered with the following anecdote:

"Yeah, for me yes. We have a little group in my hometown, with five boys, all the same age. Some are vaccinated, some aren't, with the 6-component, with less, blah blah. And I did get the impression that, well, Moriz he's called, he got the 6-component, and that he, I mean, maybe one can't say it like this, but I found it striking that he's really very very very often sick. Really very often, the flu, the sniffles, very susceptible. And my son is just much stronger, let's say. But if it's really attributable, of course one can't say, but I've noticed it."

When asked if they had also heard stories like this, the focus-group agreed that one hears stories like this one all the time. Interview Participant B told a similar story:

"[A friend of mine], she vaccinates her children against everything, REALLY everything that the market makes available. Without question. Really. And it's a very extreme example, I don't know, and yet the kids are constantly sick. I don't know if it comes from the vaccinations- one simply can't know. Could be that it's not related, naturally."

Similar stories were also told at both information sessions. At Dr. K's session, a mother asked about an acquaintance with fully vaccinated, sickly children: could it be that the vaccinations are to blame?

"Of course it's difficult to rule out a connection," Dr. K responded, "but then again many children are sick a lot, vaccinated and unvaccinated- in fact it's the consistently healthy child who's the exception, not the child who's constantly sick."

At this, a father bursts out: "But one hears these stories all the time, about vaccinated children who are sickly- maybe it's true!" At the time, Dr. K warned the group to be careful of giving too much weight to personal observations such as these, as they can lead to false conclusions. In interview, however, she also speculated that general ill-health may possibly be a sign of vaccine-effects:

"Other than an older man who was handicapped [in childhood] because of a reaction to the polio-vaccine, I've never seen vaccine-damage in my practice. What I do see however, again and again, is that parents report that since the vaccination their child is sick all the time, or has recurring middle ear infections...I probably give more weight to these stories than the parents themselves."

These stories give concrete examples of the concern that vaccination, and especially early vaccination, may weaken immune-system function, resulting in children who are frequently

ill.

Participant concerns link vaccine exposure to immune-system strain, which is seen to pose a danger to both the general health of children, and to carry with it the risk of the development of allergies and other unknown effects, resulting in the general argument for delaying vaccination until a child's immune-system can fully develop.

Vaccine-damage

For a more limited number of participants, serious vaccine-damage was cited as a major reason to refuse vaccination. Certain participants, particularly C, D, F and G, placed particular emphasis on stories of vaccine-damage as relevant to their refusal; Participants C and F, for whom these stories were matters of personal experience, cited this aspect as of key importance. Unlike the immune-system concerns described above, this area does not involve any robust, consistent storylines; when participants spoke of vaccine-damage, they told a variety of stories, quite variable in their particulars. All, however, serve to emphasize serious vaccine-damage as a matter of significant concern.

It should be noted that use of the term "vaccine-damage" was not necessarily linked to actual concern with severe complications. Several participants, particularly B and I, did use the term in interview; however, these participants failed to speak of any vaccine-effects more serious than the development of allergies, and linked these effects repeatedly to the immune-system, placing their concerns firmly within the immune-system framework. In short, the use of the popular phrase "vaccine-damage" was not necessarily a reliable indicator of the nature of individual safety concerns.

For Participant D, serious vaccine-damage was a major cause for worry. She spoke with emotion of her fear that "something terrible might happen" as the result of vaccination. When asked if she believed that vaccines in most cases grant immunity, she answered:

"Yes. Yes, I do believe that [vaccines] work. What I don't believe is that every [child] will react equally well...I just think, a healthy child is pumped full of this stuff, and it may be that that child doesn't react well to it...And I'm afraid that by vaccinating my child, that I'll do her life-long damage."

Although during most of the interview her concerns remained nonspecific, she did tell several anecdotal stories, for example of a child who had died of SIDS after being vaccinated:

"I read about it on the internet, a little girl who was vaccinated, and then that night

died of Sudden Infant Death Syndrome. One doesn't know if it was connected. The mother says yes, the doctors say no, like always...of course it's impossible to know, with the internet, I mean I don't know the people involved."

She also told the following anecdote:

"A friend of mine told me once about children who have epileptic attacks [after vaccination], and really, just stopped in the middle of their development, a two-year old child who can't speak anymore, after the vaccination. For whatever reason."

Both these stories, characterized by uncertainty, were cited as cause for worry. Participant A also spoke of the risk of vaccine-damage as a major reason to refuse vaccination, but other than briefly mentioning a possible link between vaccines and autism, she failed to illustrate her concerns specifically.

Participant G also spoke of vaccination in terms of serious danger. For example, she spoke of the practice of vaccinating infants: "I just think it's INSANE, the very idea, a BABY, newborn, or a few months old, actually to almost kill it with a giant heap of dangerous chemicals!" She spoke of the uncertain link between vaccination and multiple sclerosis, telling the story of a friend who had been in a wheelchair since the age of 17 due to this particular disorder. A homeopathic doctor attributed her condition to damage caused by the FSME vaccine: "Of course there's no way to demonstrate causality, but the doctor was of the opinion that it could be". She said that this story, despite its uncertainty, provided a strong impetus to look into the dangers of vaccination further once she herself had a child.

Family stories of vaccine-damage were key to vaccination refusal for two participants. Participant C, when talking about the beginnings of her uncertainty surrounding vaccination, told the story of two children in her husband's family:

"With [the first one], she was vaccinated, I have to say I honestly don't know which vaccine she got. But she was vaccinated, and then in the evening she fell unconscious. And then for a long time we didn't know, but now she's diabetic. I mean, the doctors say it's not from the vaccination, but we don't know, it could be connected...I mean, this is really a point of contention. The second is a bit worse, in that sense. The girl, she's eight now, she was vaccinated totally normally, and then a few hours later, not even a day, a few hours later she started having epileptic seizures, and she's still, she has to do therapy, she's lame on one side and has problems speaking. I mean, it's worse."

It was only after her oldest son came down with a severe, chronic cough after he was given the first dose of the 6-component vaccine, however, that Participant C finally decided against vaccinations for her children. This vaccine contains a component against whooping cough,

and she believes that his cough could be attributable to that component, and for fear of further complications has refused further vaccinations for her first son, and all vaccinations for her two younger sons.

"I mean, of course I don't know for sure if [his cough] is really because of [the vaccination], it's just my particular opinion, of course it doesn't have to be true. But I believe...I wonder, if he didn't somehow get whooping cough, a weakened version...he never coughed before...one can't be sure, it doesn't have to be from [the vaccine]. But before he had nothing, and then after the vaccination, a day later or whenever it started, there is a connection there, I think. At least for us."

She said she was willing to take the risk that her children catch a vaccine-preventable disease, rather than expose them to the uncertain but from her experience real dangers of vaccination.

Participant F spoke of a similar instance in her husband's family as a major reason to refuse vaccinations for her son:

"My husband's sister had, because of a vaccine, I think it's called an anaphylactic shock? She had to have her lymphatic gland removed, and she's handicapped now...a handicapped young woman, mid-thirties...she was a totally normal baby, and she just didn't react well, apparently."

For these two participants, instances of vaccine-damage within the immediate family (regardless of whether those instances can be definitively attributed to vaccination; both said they didn't know if these instances had been officially recognized as vaccine-related) provide a major reason for vaccine refusal.

In their information sessions, both Dr. K and Dr. L emphasized the potential seriousness of vaccine-damage, linking vaccines (like the participants above) to a variety of diseases and conditions. During Dr. L's session, a mother, worried about vaccine-damage, said her child had reacted well to the first two doses of the 6-component vaccine; she wanted to know if Dr. L thought it was safe to give the third dose. He took this as an opportunity to address the uncertainty surrounding vaccine effects:

"Well, you never know. We're seeing raised rates of all sorts of diseases, such as MS, diabetes, allergies, since vaccination became prevalent. Diabetes rates have increased 100% since the mass-vaccination campaigns began. And we don't know if it's the amount, maybe that third dose, that makes the difference."

Dr. K also spoke of the increase of the "diseases of civilization" in recent years and the possibility that there might be a connection between these developments and the vaccination

campaigns of the last century. She spoke of certain studies suggesting links between these diseases and certain vaccines, but also emphasized that such linkages are far from certain. She emphasized the extreme rarity of cases of vaccine-damage, but "for the parent of that millionth child who does have a truly bad reaction, these figures offer no comfort."

The anti-vaccination activist Mrs. M placed particular emphasis on the risk of vaccine-damage in her interview. Like participants C, F and G, she spoke of the relevance of personal experience with vaccine-damage, in this case instances she saw in the medical practice where she worked for many years as an assistant:

"When [the] FSME [vaccine] began, in 1978 or so, we...gave the vaccine, and right away an athletic young man came down with meningitis...he did recover after 2-3 weeks...and then we started seeing many seizures after vaccination, that started after the introduction of the whooping-cough vaccine."

She said that these experiences, alongside exposure to vaccine-critical ideas from other activist groups, provided the motivation to become an activist herself. She spoke particularly emphatically about a possible connection between vaccination and hyperactivity in children:

"I am absolutely convinced that children are so restless because of vaccination. There's so much mercury in [these vaccines]- oh no, that's not included anymore. But aluminum, that's brain-poison. They can't sit still anymore, because they're all being [exposed] to this poison."

The possibility of vaccine-damage, in short, is a major aspect of her anti-vaccination stance.

In short, for certain participants, the possibility of serious vaccine-damage is of major concern, whether that concern is based on socially-relayed stories or personal experiences. The uncertainty of these connections, or the unlikelihood of a reaction, does very little to diminish their significance in the minds of these participants.

Discussion

Most participants clearly state that safety concerns are highly relevant to their decision to refuse vaccinations; however, it is important to recognize that although these concerns do share some overarching similarities, they tend to diverge into two distinct areas.

Concerns about immune-system effects were quite prominent within the data set (with the exceptions of Participant J and Mrs. M, they were spoken of by all participants). These concerns were frequently linked to specific understandings of the immune-system's ability to cope with vaccination; subsequent effects, such as the development of allergies or general ill

health, are understood by participants to be the possible result of vaccine induced immune-system damage. The emphasis placed on the relevance of age indicates that concerns of this nature may be to a certain degree age-dependent. The 6-component vaccine was also frequently featured within these storylines, suggesting that this particular vaccine and/or combination vaccines generally may be of particular concern in relation to immune-system effects.

On the other hand, only half of interview participants spoke of significant concern with vaccine-damage, implying that serious vaccine-damage cannot be presupposed as an issue of major concern. For those who did contribute to this area, however, vaccine-damage was often spoken of as of a major worry, and for several participants was directly linked to personal experience with negative events following vaccination. Links between specific vaccines and specific disorders (such as Participant G's story linking multiple sclerosis to the tick-borne encephalitis vaccine) were however infrequent, and no consistent storylines describing specific linkages could be identified.

These two aspects also share a number of elements in common. Both groups emphasize the chemical nature of vaccines and the general wish to avoid chemical exposure. Both also emphasize the individual nature of the reaction to vaccination, specifically in terms of the ability of the individual child to "handle" vaccination. Personal and/or socially relayed stories of negative reactions to vaccination (whether minor or severe) indicate that specific vaccine-experiences are also contributing to these concerns. Finally, uncertainty is a major feature of both areas, with specific stories frequently qualified with statements such as "of course one can't know for certain", and "it could be"; however, the unquantifiable (or perhaps not-yet-quantified) nature of these dangers fails to disqualify them in the minds of participants as matters of real concern.

Chapter 3.2

Risk and necessity

Regardless of the dangers posed by vaccination, are the vaccines that are currently recommended truly necessary for the individual child? Why expose one's child to vaccines and their uncertain effects if the risk associated with vaccine-preventable disease is judged to be negligible? In this section, participants link vaccine refusal and/or uncertainty about vaccination to the act of evaluating risks, especially but not only in relation to the threat posed by disease. Risk serves as a major organizing concept for the majority of the arguments and/or concerns presented here, as expressed through the overarching metaphor of "balancing" risks or "weighing" one risk against another. The first section presents the concerns of parent who describe themselves as uncertain about the risks of vaccination versus disease, followed by a detailed description of the various arguments denying disease-associated risks and therefore the necessity of (certain) vaccines.

Uncertain balance

Several parents within the data set (primarily parents in attendance at the vaccine-information sessions run by Dr. K and Dr. L) spoke of the difficulties associated with risk evaluation in relation to vaccination. Many of the couples at these sessions described themselves as as of yet undecided in regards to vaccination, and a preoccupation with the active search for risk statistics came through in many of their questions, which often focused on the risks associated with particular diseases as well as with vaccines. For example, at Dr. L's information session, a couple spoke of their as-of-yet unmade decision to vaccinate:

Father: "What is safe? What is safety? You vaccinate, and worry about the side-effects-"

Mother: "Or you don't, and worry about the diseases."

Later in the session, another mother made a similar statement:

"For me, it's about a balance of risks. We're hearing from many sides about how dangerous the diseases can be, how bad it can be if your child gets sick, and we're uncertain about the real risk."

These parents describe their predicament in terms of risk-assessment and risk-balance, and seemed to be actively searching for information that could help them determine the "real" risk

associated with both vaccine-preventable diseases and the vaccines themselves.

Participant D, who described herself as very uncertain about her child's future vaccinations, also spoke of feeling trapped between what she described as two risk-groups:

"I am very much afraid that something will happen as a result of the vaccination. I'm insanely afraid of vaccine-damage, basically...I'm afraid that I'll damage my child's whole life if I chose to vaccinate. On the other hand I'm just as much afraid of hurting her because I don't vaccinate her and she gets some terrible disease. It's these two risk groups, really, and you can't count either out, because you can't look into the future!"

Here she describes her own situation, in which she finds herself straddling two unknown and difficult to assess groups of risk.

Dr. K addressed this predicament explicitly during her information session, during which she stressed the dangers of vaccine-preventable diseases (including measles and whooping cough), while describing instances of vaccine-damage as "extremely rare, but potentially serious":

"You are probably hearing that I'm sending you two conflicting messages. On the one hand, vaccine-preventable diseases are dangerous. But vaccines can be dangerous too. In short, this is no easy decision."

She emphasized the importance of coming to one's own decision based upon the best information available.

In short these parents, who appear to still be in the process of making a decision about vaccination, describe the uncertain balance between the risk of disease and the risk of vaccination as an important aspect of their uncertainty; Dr. K's observations emphasize the difficult nature of this evaluation.

Denying the risk of disease

The arguments presented in this section focus on the rejection of the risks associated with (certain) vaccine-preventable diseases. Five interview participants (B, C, D, H and I) cited elements from this group as central to their refusal (in response to the question "*What are your primary reasons for refusing vaccinations?*"); four others (A, E, F and G) spoke of this aspect at other points in their interview, and it was also spoken of at length by both Dr. K and

Dr. L. In short, this aspect was quite prominent within the data set.

Several participants spoke generally of the lack of threat posed by vaccine-preventable diseases. Participant I, for example, spoke of the historical importance of vaccination, linking the lack of risk today specifically to the past efficacy of vaccines:

"I know that these diseases exist, or that they existed, I know that children suffered horribly at times. And because of these deaths, people developed a vaccine...there's a history, why these things are recommended. And [the diseases] maybe aren't here anymore, because of the vaccines, which just aren't so extremely necessary ANYMORE."

Participant E made a similar statement:

"Many vaccinations were certainly important, historically speaking, lots of good was done, also many diseases exterminated. I don't deny that at all. I'm just saying I simply don't believe that everything that's recommended today is necessary."

Both link their own refusal to the perception that the success of vaccination as a public health intervention has made that same intervention obsolete.

Like undecided parents described in the previous section, certain participants spoke of this aspect in terms of risk balance. Participant B described her own process of coming to a decision about vaccinating her son:

"For me, the side-effects [of vaccination] just seem more likely, in many cases, than the diseases that the vaccines prevent. How should I put it- the possibility or the chance that you actually get a disease just seems much smaller than the side-effects that the vaccines could possibly have."

She spoke about her own allergies, and her original wish to postpone vaccination to minimize the possibility that her son would also develop an allergy.

"So I waited with it. But then at some point I decided not to do it at all, because it's just not necessary...The chance-balance is just so low, it just doesn't seem necessary to me."

She links her refusal to this process of balancing, in which she came to the conclusion that the possibility that her son would develop an allergy as the result of vaccination outweighed any threat posed by the diseases. Participant H, when asked if *vaccine-damage* was a factor for his refusal, made a similar statement:

"Yeah, I would like to avoid vaccine-damage, naturally. But fear- no, it's not a major issue for me, but it is, I mean, I also don't take antibiotics if it's not absolutely necessary...I just don't believe that it's necessary to vaccinate in many cases. There are a lot of diseases where the risk of infection is so low, I mean, it's much more likely to die in a car crash. I believe that some [vaccinations] are not necessary. And that makes them a risk."

He emphasized the lack of necessity as paramount; if a vaccine is unnecessary, he argues, even a tiny amount of risk becomes significant. Even Participant F, for whom serious *vaccine-damage* was of major concern, made a similar comparison:

"I think that I'm putting my child in danger by allowing him to be vaccinated. Really it's about balance. I mean if right now, I don't know, if measles started spreading all over the place here, and somehow many children got it really badly, and it was deadly, then maybe I would think about it, I don't know. But I would only think about it THEN. Right now, it's obsolete."

These participants are asserting the general belief that many (or all) vaccines are unnecessary, based on the lack of threat posed by vaccine-preventable disease, frequently using the metaphor of balance to demonstrate their process of evaluation.

Risk of exposure

The low risk of exposure associated with specific vaccine-preventable diseases, either in terms of *age/behavior* or in terms of *local relevance*, constituted a consistent storyline, with special emphasis on certain diseases covered by the 6-component vaccine: tetanus and hepatitis B (in terms of age/behavior), and polio and diphtheria (in terms of local relevance). Dr. L, for example, described the lack of risk posed by most vaccine-preventable diseases during his information session:

"The majority of vaccine preventable diseases, like polio and diphtheria, are no longer common in Europe, tetanus is wound associated and uncommon in babies, hepatitis B is transmitted through blood and sexual contact and therefore is also not an issue for small children."

Many participants made similar statements combining these two aspects of risk of exposure:

"Polio, for example, barely exists anymore," said Participant F, "at least not here. And I mean, hepatitis! My doctor says, as long as he doesn't have sexual intercourse or inject himself with drugs! I mean, a small child? It's sick, really, isn't it?"

And Participant I:

"Polio, yeah, what should I say, polio was around, and it was nasty. But it doesn't exist anymore, not in Europe. So why is it vaccinated against?"

Participant D, despite her uncertainty about the risks of disease, said there was a good possibility that she wouldn't give her daughter the 6-component vaccine, primarily because of its irrelevance:

"Diphtheria, for example, it doesn't exist here anymore. Tetanus, I spoke recently to a homeopathic doctor. He said, everyone thinks tetanus is so important, but it needs to go 3 or 5 centimeters into the skin for there to be any danger, and really that's very unlikely, most children just scrape themselves when they get hurt."

She also spoke of general local irrelevance, qualified by the suspicion that the vaccine-recommendations simply aren't up-to-date:

"Vaccines are given just because they were given 15 years ago. Is this at all necessary? Do these diseases even exist anymore? Is it really necessary to vaccinate such small children against so many things? One should select those that are most important, I find, and say this this and this are important, because there's really a chance they'll come."

Participant H also criticized the 6-component vaccine on the grounds of its irrelevance:

"In Austria there is no polio to eradicate. Childhood hepatitis, it doesn't exist. It's only serving to make sure that adults are vaccinated once they reach an age when they'll have sexual intercourse."

In short, although the particulars of their arguments vary, participants frequently denied that there is significant risk of exposure to various vaccine-preventable diseases, especially those against which the 6-component vaccine provides protection.

Risk of consequence

Participants also frequently claimed that the mildness of certain diseases makes vaccination against them unnecessary. The MMR trio, especially measles but also mumps and rubella, were mentioned most frequently, followed by rotavirus, chickenpox and whooping cough. This group were often described as "childhood diseases", which aren't seen to pose significant risk to the individual child. For example:

Participant B: "Mumps, measles, these are children's diseases for me, I just don't

think I need to vaccinate [against them].

Participant E: "Mumps, rubella...they're just children's diseases, aren't they? Is vaccinating really necessary?"

Some were more explicit in their denial of danger, such as Participant A:

"For me, [measles is] a vaccine that's really overdoing it. Because, one acts as if measles were really life-threatening, and it just isn't. I mean, people managed to go through it before the vaccine, and now it's blown up to be so life-threatening- it's totally exaggerated, I find."

She objected to the rotavirus vaccine on similar grounds:

"I mean, if a child really gets severe diarrhea, it's rarely deadly. I mean, it's not like in the 3rd World where there's no access to treatment. Maybe for a very weak child who has some other problems, who's already weak. But for a healthy child, it seems excessive."

Participant D (as well as Participant C and Dr. L) also objected to rotavirus on these grounds, repeating here the advice she was given by a conventional pediatrician:

"It's uncomfortable, naturally, this rota-infection. But it's not, actually not deadly for the child, you know? I mean maybe you have to go to the hospital, the child gets an infusion, sure it's uncomfortable, but somehow that seems preferable to me than to pump live-vaccines into the kid instead, when it's highly probable that in the majority of cases it's simply completely unnecessary."

Dr. L put quite a lot of emphasis on the lack of risk presented by this group of diseases in his information session:

"Of all the cases of these diseases, 90% are harmless, they're not even recognized and pass without a doctor's visit. Of the cases that manifest more strongly, 90% are treatable with homeopathy, antibiotics, and so on."

A mother asked specifically about the risks associated with measles, and Dr. L answered, "one death per 10,000, one death per 100,000, I don't know the exact figures." In interview, he again emphasized the harmlessness of certain diseases:

"It's understandable that one [should want to have] a means to protect children from complications, but it's a difficult question, above all in respect to this constant expansion [of the recommendations]. Chickenpox, simply not of concern even today, and in my time measles, absolutely no danger, no one was afraid of measles!"

For these participants, the complications that might arise due to the particular disease simply aren't deemed dangerous enough to warrant vaccination. Although evaluation of particular diseases varied from participant to participant, many participants believe that particular vaccine-preventable diseases simply aren't dangerous, making vaccination against these specific diseases irrelevant.

Exceptions prove the rule

Many participants made exceptions for certain vaccinations, in particular for FSME (against tick-borne encephalitis) and tetanus, as well as for travel and other specific considerations. Tetanus and/or FSME in particular are unique, many participants argued, in that there exists both a risk of exposure to the disease in question, alongside significant risk of major complications and/or death upon infection. For these two reasons several participants selectively vaccinated their children with one or both of these vaccines³⁷. For example, Participant B spoke of her decision to selectively vaccinate her three-year-old: "When he turned two I read through everything again, and I mean I can't repeat it now, why I made that decision, but tetanus was important for me." When asked if her decision had to do with the severity of the illness, she responded:

"Yes, because of the effects, and because children do injure themselves sometimes, and with lockjaw, as a result...I thought yes, it's okay if he gets that [vaccine]. And the tick-protection vaccine, because we come from Styria, and there, the region, it's rather dangerous, with red ticks, and with meningitis, I really didn't want to take responsibility for that."

Participant E, whose child was also vaccinated against tetanus and FSME, also spoke of the FSME vaccine as particularly relevant owing to the the risk of infection:

"Ticks, that's a classic really. As one says, because children run around a lot in the woods, and the ticks, also statistically, they say the distribution, the red regions, and you think well, at least the danger that one gets a tick is relatively high...I just have the feeling that the chances are higher that one gets it, based on the tick-distribution in Austria etcetera. That there really is a chance, maybe it's that."

Even certain participants who saw the risk of serious vaccine-damage as a major worry spoke of the relevance or irrelevance of particular vaccines as an important element of refusal. Participant A, for example, when asked if she intended to vaccinate her child in the future, spoke

³⁷ See the Participant Data table on page 24 for the vaccination status of participants' children at the time of interview.

about the FSME vaccine:

"The only vaccine that I might consider would be the tick-protection vaccine, against tick-borne encephalitis. Because we're in the woods often...and I think, in this case, the benefit is perhaps really greater than the harm...since there really are regions where it's really, where there's a serious tick infestation."

She also said that in the case of injury she would have her daughter vaccinated against tetanus (she believes the vaccine to be effective when administered post-injury). Even Participant C, who's experiences with vaccine-associated adverse events have caused her to have major doubts about vaccine efficacy and safety, spoke positively of the tetanus vaccine:

"The only vaccine that I might consider at some point, since the children as we speak are playing outside, would be tetanus...because the kids, I don't know, they could get hurt...that's the only one where I think okay, that's somehow probable. So, for the protection."

She also spoke about the FSME vaccine:

"That one makes sense in some ways, because meningitis, that's really something, and that one gets [an infection from] a tick, that can really happen I think, I know someone that really did get it."

Participant H, who gave his daughter the single tetanus vaccine, explicitly contrasted the risks associated with tetanus with other diseases covered by the 6-component vaccine. He said that his doctor recommended tetanus,

"...not because with tetanus there's evidence that the vaccine works and results in fewer instances of damage. It's more because with tetanus, if you get it once, you're simply dead. And all the others, or, yes actually all the childhood diseases that you can vaccinate against are simply diseases that in most cases run their course without problems."

He placed particular emphasis on the fact that it's the severity of a tetanus infection, and not the lack of danger posed by the vaccine, that motivated him to accept it, coupled with the perception of a real risk of exposure:

"[With tetanus], one also can't shield children from the pathogen. Many, for example, what else is there, hepatitis B, completely absurd...I mean, the 6-component vaccine, it contains polio and hepatitis B. And the probability of contracting tetanus is simply so much higher."

Positive participant evaluations of these two vaccines are based upon the combination of the same two aspects relevant to denial of necessity: risk that the individual is exposed to the disease, coupled with the risk that the individual is damaged by it.

Participants also made exceptions for other considerations, such as travel or age-associated risks. All participants, with the exception of J and F, said they would consider certain vaccinations for their children if traveling to a country where there was significant risk of infection. Focus-group Participant 2, for example, said she would consider vaccinating her daughter against tetanus in the case of travel (she believed the disease to be a danger only in areas of the world with insufficient hygiene standards); more frequently, polio or hepatitis were used as examples. Participant G spoke specifically of the polio vaccine as possibly relevant in the case of travel:

"Polio is still an open question, if [my daughter] ends up traveling to a country where it's still a problem...say to the Indian Subcontinent or somewhere like that, I would make inquiries again, and if the people that I trust to advise me recommend that she be vaccinated, then I would try to get the least harmful vaccine [for her]."

Like Participant H, Participant G indicates that proven necessity overrides the possibility of vaccine-associated risk (although she explicitly states that she will take precautions to reduce that risk). Participant A was less hesitant about vaccinating in case of travel:

"Vaccines can certainly be good too, if you go traveling, where you know that there's a high probability that you might catch hepatitis or something like that, then you have to give in and do it."

Dr. K very specifically pointed to travel as a good reason to vaccinate during her information session, giving the example of her own daughter, who was first vaccinated against polio when she traveled to Egypt as a young teenager. She also spoke of the onset of puberty as an important time for certain vaccinations, in particular rubella, mumps, and hepatitis B. Participant A also pointed out that it would become necessary to vaccinate her daughter against rubella once the girl reached puberty: "I mean, with rubella, that's another story, for girls, since during pregnancy, since it can be dangerous for the baby, that's something else, there's a real benefit." Similar statements about the relevance of rubella (for girls) and mumps (for boys) were made by participants G and H, as well as during the focus-group discussion.

Discussion

In this section participants question the necessity of vaccination, often coming to the conclusion that the majority of vaccinations, under most circumstances and especially for children, are simply unnecessary. Although individual diseases were evaluated differently by different participants, two criteria, risk of exposure and risk of complication, appear to be of key importance. Participants were nearly unanimous in denying that their individual child's vaccination status put them at risk, whether due to the local irrelevance of the particular disease, or to its mildness; all the arguments in favor of certain vaccines, from tetanus and FSME to travel-vaccinations and age-relevant vaccines like rubella and mumps, also hinge on these twin elements. In short, when put in the balance, many participants find that the uncertainties surrounding vaccine safety outweigh the low levels of risk posed by disease; as articulated by Participant H above, this lack of necessity makes even the most improbable danger (such as the possibility of vaccine side-effects) worth considering. Only diseases judged to fit both criteria were identified as worth vaccinating against by participants, suggesting that the perception of individual risk may be key to vaccine acceptance in this context.

A significant feature of these arguments, though often implicit, is a positive evaluation of basic vaccine efficacy. Though contributing participants vary in their evaluation of the functionality of vaccines (to be addressed in the following section), the exceptions made by many participants for key vaccines/diseases implies at least a certain degree of faith in the general efficacy of vaccination (as does the selective vaccination behavior demonstrated by several participants: see Participant Data Table, page 24). The emphasis placed on individual risk indicates that questions of necessity, as viewed from the perspective of the individual, may be of significant relevance to vaccine acceptance, and may potentially override concerns about the uncertainty of vaccine safety or efficacy if disease-associated risks can be convincingly demonstrated.

This focus on individual interest also indicates a problematic relationship with the communal aspects of vaccination programs, specifically the establishment and maintenance of herd immunity. It has been risk to the individual that has taken the foreground in these pages, while other forms of risk, in particular the communal or population-level risk foregrounded by the concept of herd immunity, were not acknowledged as relevant to the vaccination decision by participants. It's interesting to note that both tetanus and tick-borne encephalitis are diseases that are incommunicable, and neither is solely reliant on the human host and

therefore cannot be eradicated or protected against through herd immunity (Lindquist & Vapalahti 2008, Hinman 1999), making the decision to accept these vaccinations a truly individual one. For other diseases however, in particular polio and the trio measles, mumps and rubella, herd immunity is very much a relevant consideration (Aylward et al 2000). Ambivalence towards the herd immunity concept was indeed spoken of by participants, to be addressed in detail in the coming pages.

Chapter 3.3 Do vaccines work?

Do vaccines actually do what the experts say? Do they provide individual immunity; and even if they do, is it really high vaccination rates that are protecting the European population from the influx of vaccine-preventable diseases? When asked if they thought that vaccines work (in the sense that a child who is vaccinated against a particular disease will most likely become immune to that disease as a result), half of interview participants, specifically A, B, D, E and I, responded, without hesitation, yes. Others, however, expressed varying degrees of uncertainty about the efficacy of vaccines, falling into two distinct categories. The first, *uncertain efficacy*, is characterized by a focus on specific instances of possible vaccine-malfunction, while the second, *the hygiene argument*, focuses on uncertainties surrounding the population-level effects of vaccination campaigns.

Uncertain efficacy

A minority of participants spoke of basic vaccine efficacy as problematic. The following storylines address two aspects of vaccine malfunction linked by participants to uncertain efficacy: a) that vaccines can cause the disease they're meant to prevent, and b) that vaccinated individuals sometimes become infected despite vaccination³⁸, as demonstrated by personal experiences, socially-relayed anecdotes, and/or the interpretation of media-reported events.

Vaccines cause disease

Certain participants linked doubts about vaccine efficacy to suspicions that vaccines may in fact cause disease. Although this storyline was only spoken of by Participants C, F, and Focus-group Participant 1, all three placed a large degree of emphasis on its importance, and both participants C and F spoke of this aspect as primary grounds for refusal.

Focus-group Participant 1, for example, spoke like many participants about the relevance of the tetanus vaccine; she said that she was considering giving her as-of-yet unvaccinated son the diphtheria-tetanus combined vaccine "...because, according to what I read back then, that's

38 A certain percentage of individuals will indeed fail to develop immunity after a properly administered vaccination series, what is known as "non-response". The hepatitis B vaccine, for example, has non-response rate of < 5% (Centers for Disease Control and Prevention 2012:132-33).

the only [vaccine] that, well, that somehow makes sense." When asked why, she didn't speak of the severity of the disease or risk of exposure. Instead, she answered: "That the vaccine really can help, if one gets sick," implying that in her opinion most other vaccines in fact can't protect against infection. She went on to tell a story from her child's daycare, of a little boy who was given the MMR vaccine and immediately came down with measles, mumps, and rubella simultaneously. "He eventually got healthy again- but really, he was really sick." As she described it, the child had contracted these diseases from the vaccine he was given.

When asked if she thought vaccines work, Participant F answered with a similar story, this time about the rotavirus vaccine:

"Okay well, I mean, there are also descriptions of cases where because of the vaccine [people] come down with exactly that illness. I mean- I can't really assess [vaccine efficacy], and I don't want, I mean, if it's like this or that, scientifically, I really haven't looked into it. Sure, it could be. It could be, of course, that in many cases the [vaccines] repel [the diseases]. But there's also, [the child of] an acquaintance of mine, she got this rotavirus, I think it was. She was vaccinated against it, and a few months later she landed in the hospital, and they found rotavirus in her gut. She really was terribly sick, the child. And the mother said, what would have happened if she hadn't been vaccinated? And my opinion is, couldn't she have gotten it FROM the vaccine?"

Participant F described such stories as one among a list of reasons to refuse vaccination.

Stories of vaccines causing disease were most emphasized, however, by Participant C, for whom this phenomenon was a primary grounds for vaccination refusal. When asked if she believes that vaccines work, she answered with a sigh:

"Yes and no, yes and no. Of course it could be, if you really get something, maybe it can work...but for example, my husband had himself vaccinated against the flu, and then of course he got a proper flu and was in the hospital for a while, and then he thought okay, what was the point of getting vaccinated? He was vaccinated. And it was bad...I mean, for the kids, of course it's uncomfortable if they really get [something like measles], but I think, I think if they get it, then one probably couldn't have stopped it with a vaccine. That's just my opinion. It probably just depends. It can still be that they get it, even if they're vaccinated. And above all, for example many claim that in fact they can get it BECAUSE of vaccination, I've also heard that."

She spoke of several instances of vaccine-induced infection during her interview, including an experience with her oldest son, who she suspects contracted a weakened form of whooping cough from the pertussis component of the 6-component vaccine (see page 33-34). She also spoke of studies demonstrating that vaccines can sometimes cause disease, and told another personal anecdote, this time about rotavirus:

"Yeah, rotavirus, that one I think is completely senseless. I mean for example once again I can tell you about a friend in Styria, she gave her little one the rotavirus vaccine, and still he came down with it and landed in the hospital...I mean, honestly, one has to say that there are studies, for example, where children, really there are a few studies on it, that sometimes the diseases occur because of vaccination."

For these participants, suspicions that vaccines may not do what they say they do resonate with personal experiences or socially-relayed stories of disease instance after vaccination.

Vaccine failure as evidence of inefficacy

A closely related storyline also points to instances of disease in vaccinated individuals, not to suggest that vaccines can in some cases cause disease, but to demonstrate that vaccines can fail to provide protection; instances of failure are taken as possible proof of general inefficacy, with links to potential conspiracy. This storyline was mentioned briefly by a single interview participant and was spoken of in detail by only one focus-group member; it was however a major focal point of anti-vaccination activist Mrs. M's interview, and has thus been selected for inclusion.

Participant G spoke of vaccine efficacy as uncertain, based on studies conducted in the United States showing "...that in the last 20 or 30 years, there have only been 17 cases of tetanus, and HALF of [the victims] had been vaccinated", insisting that this fact calls into question the basic efficacy of the tetanus vaccine. Focus-group Participant 2 spoke in more detail of a similar example:

"[Vaccines] are somehow supposed to give parents security, but it's not really followed through on in the end, I think. For one thing vaccines demonstrably don't work like they should. I don't know if you all can remember, it was about two years ago, a measles outbreak somewhere. It was at a Waldorf school, they all weren't vaccinated. And somehow, what was so conspicuous about it was this other school where there were also a lot of measles cases, where they in fact were all vaccinated. I tried to find out, if it was at all possible to find out, if from those who were sick, if they really had been vaccinated, but it just wasn't possible. I called [a local anti-vaccination organization], and [they] said that [they] also couldn't find out, that the data was being kept secret."

Both these participants interpret instances of vaccine failure as possible proof that vaccines in fact don't work, or at least not as they should, as Focus-group participant 2 phrased it; that these facts are possibly being "kept secret" by the authorities serves to exacerbate these suspicions.

Mrs. M, however, was the sole participant within the data set to flatly deny vaccine efficacy. In interview she used a similar example as the one given by Focus-group Participant 2 as evidence that vaccines are universally ineffective: "In epidemics, over 50% of those who get infected are always vaccinated. If the vaccines really helped, not one single [vaccinated individual] would get sick." She explicitly denied the relevance of vaccination, even in areas where serious vaccine-preventable diseases are still endemic. She spoke for example of the African Continent: "In these countries, where there's still war and famine, it's these conditions that lead to disease, not lack of vaccination." She denied the relevance of the infant tetanus campaigns in these areas by linking raised rates of infant tetanus to maternal under-nourishment. She spoke of the "aha-moment", near the beginning of her career as a volunteer anti-vaccination activist, when she realized that "vaccines don't protect", and that pure economic interest lies behind national and global vaccination programs. "It's all manipulated, everything steered by the pharmaceuticals industry", from the Austrian Medical Association and the Ministry of Health to the media and the medical establishment. She spoke of the dream of her organization, to discontinue vaccination for three years: "...and we would all be healthy and happy. We don't know anymore how healthy we would be without vaccination. Dreadful!"

Mrs. M's narrative proposes what amounts to world-wide conspiracy, involving numerous governments and much of the medical and scientific establishment; she uses instances of vaccine failure to promote her vaccine-critical agenda, which universally denies vaccine efficacy. No other participant spoke so broadly of efficacy-related conspiracy or cited this particular storyline as a major grounds for vaccine refusal; for a few participants, however, uncertainties about vaccine efficacy are linked to suspicions surrounding the honesty and/or integrity of the health authorities. This aspect of vaccine-skepticism, which connects vaccine policy and promotion generally to the powers of industry, will be addressed in detail in Chapter 3.6.

The hygiene argument

A number of participants (C, E, G, H, and J, as well as Dr. L and Mrs. M) were critical to some degree of the population-level effects of vaccination, and especially of the efficacy of herd immunity. According to the herd immunity concept, high rates of vaccination make it impossible for a specific disease to "break out" within a population, thus providing protection

not only to the vaccinated individual, but also to those members of the population who cannot be vaccinated (such as infants and individuals suffering from certain conditions), as well as to those who were vaccinated but failed to develop immunity³⁹. In the following storyline participants problematize the relevance of vaccination generally and herd immunity specifically by questioning the causal link between vaccination campaigns and the reduction of disease rates, citing other factors, especially advances in medicine, hygiene, and nutrition, as of underplayed significance; some go so far as to suggest that it is indeed these health and lifestyle factors, and not vaccination, that are responsible for Europe's low rates of vaccine-preventable disease.

Participant J, for example, when asked whether or not he believes vaccines work, answered by jumping from the individual to the population level:

"I should just point out that I'm not a physician, and I'm only moderately interested in [medicine]. I'll say in general, I think it's great that the field of medicine exists. The claim that certain diseases aren't around anymore because of vaccines I would have to examine more closely. As a lay-person I would say that once again this falls into a sphere where other parameters also apply."

Several participants spoke of the uncertain connection between vaccination and sinking disease rates, frequently citing public health and lifestyle factors, in particular hygiene and nutrition, as important elements contributing to the disappearance of infectious diseases. Participant E, for example, generally accepts vaccine efficacy, and said he believes that vaccination played an important role in improving public health in Europe in the past. However, he spoke of the mono-causal linkage of disease reduction to vaccination as unsatisfactory:

"Sure, life expectancy is always increasing, but not just because we vaccinate more, also because medicine is more effective overall...above all at our latitude, I mean, when you think about it, [in the past] we had totally different hygienic conditions. I mean earlier maybe we lived badly, and everything wasn't so good, and then it was more important [to vaccinate] than it is now."

When asked if he feared that wide-spread vaccine refusal might threaten herd immunity, he also answered hesitantly:

"Through globalization, it's true, [these diseases] could come back quickly. I don't know, if lots of people decide not to get vaccinated, maybe the diseases will return at some rate. At the same time, medicine is already quite advanced, and so is the hygienic situation. And disease occurrence often has to do with hygienic

39 <http://www.vaccinestoday.eu/vaccines/what-is-herd-immunity/>, accessed 5.6.2012.

conditions."

Although he sees basic vaccine efficacy as unproblematic, these statements express a degree of ambivalence about the relevance of herd immunity.

When asked about vaccine efficacy, Participant H spoke of uncertainty surrounding efficacy at both the individual and the population level, again pointing to the significance of hygiene and other lifestyle factors:

"This is a bit of a side question, actually. Do vaccines work? And, um- the question is, WHICH vaccines work? And the problem with epidemiological data is that establishing causality simply isn't possible, period. It just doesn't work. And with the real showpieces like polio, it's clear that concurrent with the mass-vaccination campaigns, that there has been so much improvement in the general hygiene-situation, and the nutrition-situation, that you simply can't unequivocally ascribe the retreat of polio to vaccination."

He questioned the validity of the herd immunity concept, again pointing to other health factors like hygiene as possibly more relevant than vaccination:

"[Maintaining herd immunity] is a very common argument [in favor of vaccination]. But the question is simply if it's correct. No one actually knows, for example with polio, because vaccine coverage has been established for so long, and at the same time so much has changed regarding hygiene and nutrition. That, yeah, I don't know."

He said that for him, vaccine-efficacy is an open question; he pinned his own vaccine-refusal to issues of necessity which make efficacy-related questions relatively moot.

Some participants explicitly insisted that it is indeed factors like nutrition and hygiene, and not herd immunity, that are currently protecting Europe from many vaccine-preventable diseases. When asked about her estimation of vaccine efficacy, for example, Participant G answered by expressing significant skepticism about the effectiveness of vaccination as a means of disease reduction:

"If I try to summarize I feel uncertain, because I'm not sure anymore if I would say that vaccines work, or if they don't. Because from what I remember, it's the development, the improvements in people's nutrition and in hygienic conditions, that [these factors] have a much greater effect than vaccines, and that it's a dangerous misinterpretation of data to say that it's because of vaccines that humanity has survived. I know of analyses, from studies, that are very skeptical of the causal link, that the vaccines really are the primary cause [of disease reduction]."

She describes here her own suspicion that vaccines have little to do with disease rates in

Europe, and that in fact it's public health and hygiene measures that are keeping vaccine-preventable diseases at bay.

Participant C spoke of a similar lack of faith in herd immunity as a significant factor for today's disease rates:

"Maybe vaccinations helped in the past, I mean, it's hard to say. But in principle, I just don't think that one really needs it, vaccination...In Austria, today, I don't think you need to vaccinate."

When asked to explain, she continued:

"I just think, these days, vaccination just isn't so necessary, in the sense that, because of cleanliness standards...These diseases, they just don't exist like they did in the past, they'll be eradicated soon enough I'd say. Many say because of vaccination, of course- I'd say on account of hygiene, simply because of hygienic standards."

At other points in the interview she spoke of the relevance of certain vaccines (such as tetanus and FSME), as did Participant G, who would consider giving her child the polio vaccine in case of travel; this implies that neither reject vaccine efficacy at the individual level (at least not entirely), but both have major reservations about the efficacy of herd immunity.

Dr. L also emphasized the importance of hygiene for disease rates, implicitly problematizing the herd immunity concept. A father at Dr. L's information session asked whether or not one should worry about diseases like diphtheria coming to Europe from other countries; in response Dr. L showed the group a graph demonstrating that diphtheria rates in Europe were already in decline before the introduction of the vaccine⁴⁰, explaining:

"Hygienic standards and access to proper health care have most likely done just as much to shield Europe from these diseases as the vaccines have- in any case these other factors are important."

Mrs. M spoke of a similar argument posed by Dr. Gerhard Buchwald, in which he demonstrated using "lots of graphs and statistics" that the diseases have disappeared because of quality of life, not vaccination. All these participants are expressing doubts about the protection provided by vaccination at the population level, pointing to factors beyond vaccination as either competing with or even overshadowing the relevance of vaccination as a

40 To be found in a vaccine-critical pamphlet published by the Swiss Foundation for Consumer Protection (*Stiftung für Konsumentenschutz*): see <http://konsumentenschutz.ch/shop/detail/ratgeber-impfen.html>, accessed 13.7.2013.

public health measure; the unquestioning acceptance of herd immunity as a protective force is clearly problematic for these participants.

Discussion

These two areas of efficacy-related concerns, in which participants questioned individual-level efficacy on the one hand and population-level efficacy on the other, were distinct from each other in terms of both participation and relevance, and appear to be linked to different aspects of vaccine refusal.

Although doubts about efficacy at the individual level were spoken of by only a few participants, these doubts were cited as important or even central to refusal by most participants who did mention them. There also seems to be a rather strong connection between these concerns and concerns with vaccine-damage. Participants C, F, G and Mrs. M were primary participants in the *uncertain efficacy* storyline; these four participants also spoke at length of *vaccine-damage* as a major concern (see Chapter 3.1). All four placed special emphasis on personal stories of both vaccine-damage and vaccine malfunction, suggesting a possible connection between serious safety concerns (especially those based on personal experience) and efficacy doubts.

The *hygiene argument* was spoken of by a number of participants as a reason to doubt vaccine efficacy; however, no participant cited this storyline as a major reason to refuse vaccination. It is possible that this argument may instead be serving as an explanatory model supporting the denials of vaccine necessity described in the previous section of this chapter. By calling the population-level efficacy of vaccines into question, participants are again problematizing the need for vaccination; for if herd immunity is indeed irrelevant, there is no logical reason why communal interest should take precedence over the interests of the individual, implicitly discounting the element of social responsibility that is often linked to herd immunity maintenance.

Chapter 3.4 Alternative concepts and values

This chapter has up until now focused on grounds for vaccine refusal which have directly to do with qualities possessed (or lacked) by vaccines themselves. A number of participants, however, also spoke of vaccination refusal within a broader context, connecting the choice to refuse vaccinations to more general ideas about the nature of health, the value of disease, and the possible impacts of medical interventions.

Several interview participants are absent, or nearly absent, from these pages (B, C, E and I); others, such as Participant G and especially F and J, speak more loudly in this section than in most other areas of the report. The influence of certain schools of alternative health, specifically homeopathy and anthroposophy, are also more evident in these storylines than in other areas of the report, and in some cases are explicitly referenced. However, the ideas underlying these storylines, including the holistic nature of health and illness, the beneficial nature of the disease experience, resistance to disease eradication as a public health goal, and the general wish to avoid unnecessary medical treatments, cannot be bracketed off from more mainstream concerns, and are relevant to other aspects of vaccination refusal.

Holistic health concepts

Many of the participant statements in the coming section place special emphasis on the holistic nature of health. In contrast to medicalized conceptualizations in which health is linked solely to the absence of somatic disease, several participants spoke of the importance of non-material factors, such as the psyche and emotions, as an important part of health and well-being. In general, a holistic approach to health can hardly be considered alternative; the World Health Organization, for example, has defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" since 1946⁴¹.

A few key participants spoke explicitly of health as a state in which a variety of aspects, both material and immaterial, are brought into balance. Participant J, for example, equated health with holistic balance, in that

"...every organism wants to bring itself around to a harmonious state. Harmony means the absence of disease, a person's well-being, connection to the earth, emotional well-being, the ability to be happy and rejoice when the sun is shining.

41 See <http://www.who.int/about/definition/en/print.html>, accessed 17.9.2013.

That's what health means for me."

His definition of health thus includes both physical, objective aspects (such as the absence of disease) and subjective, psychological or emotional aspects (such as the ability to be joyful). He spoke of the "prophylactic support" of homeopathic treatment as all that was necessary to keep his daughter healthy since the day of her birth, emphasizing in particular the importance of the non-material factors that in his opinion are ignored by conventional medicine.

"Health isn't just the absence of disease, for me the social-spiritual aspect is much more significant. If I feel well, in my soul⁴², then diseases can't breathe so easily. That's more my approach. I'm more inclined to think it's because of missed signals that one reaches the point where you have to look at and treat crass physical symptoms. There were much subtler signals, earlier, that one simply didn't notice. It's a question of perception."

An acute awareness, he argues, allows one to notice and respond to signals of imbalance (regardless of the material or non-material, emotional, physical or environmental nature of these signals) before that imbalance has become severe enough to result in physical symptoms.

Several participants connected this approach specifically to homeopathic health concepts, which view disease-associated symptoms as indicators of an underlying "imbalance", the causation of which is impossible to link to a single reductive factor (such as a bacterial or viral infection) and which necessitate holistic consideration. Although Participant J's statements imply a certain ambivalence towards conventional models of infection, Participant F spoke explicitly of the germ-theory of disease as problematic:

"For me it's suspect, this idea of infection. The interesting thing is that not everyone gets infected, you know? There are people who doubt that contagion exists at all...they say, according to classical homeopathy, for a homeopath it doesn't matter if it's a bacteria, or a virus, or nothing. He would say, it depends. Sometimes it's literally NOTHING, and yet you have the same symptoms as someone who has a bacterial infection. So instead they look at the whole person. And when the whole person is healthy, he also won't get infected."

Later in the interview, she qualified her statement:

"What is contagion? Does it really happen because of bacteria? Naturally we know about Semmelweis, and what all. Lots of children died, and then the midwives started to wash their hands more often, and it was better. Yes, certainly, very well, very well. But I believe that you can't see it as such an absolute."

42 In German, the term "*Seele*" can be translated as soul or spirit, but also as mind or psyche.

Mrs. M, who worked for many years in the reception of a homeopathic physician, also emphasized the importance of holistic considerations for health, including widely acknowledged sources of ill-health such as poor nutrition and lack of exercise or sleep along with psychological/relational factors, such as the impact of chronic social conflicts:

"For example, if [a man] has fought with his sister for his entire life, then you don't even need to try to get healthy, you know? There are so many [examples of situations] that simply drain [a person], and you can't factor it out. [We] saw extreme cases like this, people who wanted to get healthy, and [the doctor] told them 'go and come to some sort of reconciliation, and then come back'. One underestimates [the importance of] this."

Dr. L also spoke of the importance of holism, saying that rather than focusing reductively on disease, he strives in his practice to focus on health and preventative measures,

"...and that hangs together with homeopathy, the gentle and natural approach to people, that's really the background...don't just see people as organs! For me it's important to view each person in their particular context, in their environment."

This holistic approach emphasizes the importance of the balance of a multitude of factors, including (but not necessarily limited to) the material/physical and the psychological/relational, as key to health; this basic understanding of the nature of health underlies the alternative understandings of disease and treatment more closely linked to vaccine refusal that dominate the coming pages.

Positive aspects of disease

Several participants spoke of reasons to refuse vaccination that had less to do with the vaccines themselves, and more to do with the desirability or value of the diseases that vaccines are meant to prevent. This aspect was emphasized as an important grounds for refusal by certain participants, in particular participants A, F, G, H and J, as well as all three members of the focus-group. Participants who addressed this aspect often emphasized the importance of natural processes, especially in relation to the development of strength, a healthy immune-system, and/or holistic development.

This aspect first arose during the focus-group discussion. Participant 1 placed particular emphasis on the importance of natural, uninterrupted development, speaking here of her

primary reason for refusing all vaccinations for her 3-year-old son:

"I don't want to intervene in the organism as long as it's still developing. With babies, with young children, they're still in the middle of it, this process, and I don't want that disturbed in any way, not to intervene in this development, not to disturb the natural progression of things".

Later on, focus-group discussion turned to the link between natural development, strength, and the experience of certain diseases:

Participant 3: "Chickenpox, really, sometimes I just don't see any reason why children can't just live through these diseases."

Participant 2: "Yes! Maybe certain diseases just go along [with childhood], maybe it's not very comfortable in the moment to go through it, but that it's then positive for their development, that disease is not necessarily something bad, that one should avoid at all costs."

Participant 1: "Exactly..."

Participant 3: "For me it's also that the organism develops naturally, and prepares itself well for things like viruses, and that when disease comes, that there's a point to the disease, and that there's trust, that I trust my children to grow and to get stronger."

All three focus-group participants agreed that natural development, which includes the experience of certain diseases, may well be beneficial for a child's overall well-being and/or physical strength, thus problematizing the desirability of vaccination.

Participant J cited a philosophy of naturalness as a primary grounds for refusing vaccination, again emphasizing the avoidance of interference or intervention. When asked to describe his primary reason for refusing vaccination, he answered:

"I believe in every form of naturalness. I believe that in every organism, if it's left alone- in this form of healing, let's say. That no one knows better what needs to be done than the organism itself. No one better."

He also directly linked vaccine refusal to the desirability of the disease experience, in contrast to intervention through exposure to vaccines:

"That is my formulation, that I believe that it makes no sense these days to artificially pump foreign material, above all childhood disease germs, into a body, on the assumption that that would be better than going through the actual disease."

He spoke of his own experience with childhood diseases, which he connects to his robust

health today:

"I still remember having measles as a child. I was sick a lot. I also had rubella and the mumps. And I can remember how glad I was to be sick, also uncomfortable of course, a purgatory time. And when I read now about how important childhood diseases are, how important for the organism. It's training... I had the measles, was in bed with fever-nightmares, and if that's the price I paid so that today I'm very stable, I say THANK YOU. And I'm happy that my daughter also had the measles."

Again, certain disease experiences are seen as an important aspect of natural childhood development, problematizing their avoidance through the vaccination.

Some participants spoke not only of the strengthening aspects of certain disease experiences, but also of their importance for a child's holistic development. Participant A, for example, spoke in particular of measles as strengthening:

"I mean, I'm sure that out of 1,000 children, a few will really develop complications. But the rest get through it, and I'm sure they're stronger afterwards, in terms of the immune-system."

She also spoke certain diseases as providing holistic benefits,

"...not only physically, but also psychologically, for everything...I mean, [for example with chickenpox], the child is sick for a week, and I'm sure there's a reason to get it as a child, and that it's also important."

When asked what it might be important for, and she responded:

"For the immune-system. And maybe also for the development, for childhood development. Not just physical, but also psychological, for everything...I'm sure there's a point to these diseases. These childhood diseases, I'm certain it's better to go through it."

Participant G also spoke of childhood diseases such as measles, mumps and rubella as being of particular value in that they encourage the holistic development of the child, a concept that she linked specifically to the ideas of Rudolf Steiner. She spoke of the strong influence of a close friend who had raised her four children according to the tenets of anthroposophy; this friend said that each illness her children experienced was followed by a leap in development, and that these illnesses were very important for the child to experience, "...that childhood diseases are essential for the holistic, emotional, psychological and physical development of a child." She spoke of her own vaccination refusal as a conscious decision not to take this opportunity away from her own daughter.

Participant F was particularly emphatic about the positive nature of the disease experience, describing here the positive effects of illness that she had witnessed in her own child:

"With my son it's really extreme, when he's sick, afterwards, he's gone through such a development, in terms of his personality, it's really amazing!"

As an example she described a rather worrying bout of diarrheal illness, after which her son experienced a sudden leap in language abilities:

"Each illness was a developmental step for him. And we're of the opinion that diseases are a part of life, and mean further development. And if I take that away from the child, he's missing out on something, basically."

According to these participants, the natural disease experience, which is seen to promote physical strength as well as in some cases holistic growth, makes that experience desirable; intervention through vaccination is seen as interference with this beneficial, natural process.

Questioning eradication goals

All of the above arguments imply a degree of ambivalence towards disease eradication as the ultimate goal of campaigns against infectious disease; a few participants spoke explicitly of this aspect as an element of vaccine refusal. Participant H, who did not speak of the disease experience as valuable at the individual level, did wonder if specific diseases might not have an as-of-yet undiscovered but nonetheless important role to play for human health in general. Here, he describes one of his primary reasons for rejecting vaccination:

"There are certain diseases, such as measles-mumps-rubella, where you could say there's been thousands, no millions, actually, millions of years of co-evolution of pathogens and mammals, and that many pathogens have importance for humans, or for other mammals, also for the regulation of their own health. And to insist on avoiding diseases through [vaccination], I don't know, for me the argument that this is good isn't so convincing."

When asked if he was referring to the argument in favor of disease eradication, he answered:

"Yes, exactly...I mean, there are diseases that are chronic or deadly, I don't know, malaria, or hepatitis C, or such things. Of course they pose a problem. But then there are other diseases that aren't deadly in the vast majority of cases, or that pass by without truly serious complications. And in that case it's simply not clear to me if there isn't something good about the fact that these diseases exist. It's a simple

viewpoint. I don't know what they should be good for, exactly, but I'm just not certain that they're not good."

Participant G described her own surprising take on disease eradication by reversing the standard argument of social responsibility in relation to vaccination, stating that diseases like measles are valuable enough to human health that she's willing to risk even her child's life in order to increase the possibility that those diseases will survive into the future:

"I find it very difficult to talk about it with anyone at all, since my opinion would shock many people, it's just not possible to talk about it...it sounds to many people so hard and inhumane, like dealing with garbage or the environment or other social questions. In some cases the difficult decision is to decide for the majority, and against myself or my child. That is, that I find it so important, to consider the health of humanity in three or four generations, that I think, this sounds really inhumane, but that it's more important to think about the health of children that aren't yet born, than to just think of my own child!

In her opinion, measles is so important for the health of the human population that she'd rather run the risk that her child has the disease and suffers a fatal complication than see the disease eradicated.

Dr. L, both in his information session and in interview, focused specifically on the possible effects of what he described as "interference with the ecosystem through vaccination":

"For me, the main question is, is vaccination useful in the long term? Sure it makes sense for individual children who perhaps avoid these complications, but the question is if this suppression and eradication of diseases within the ecological system, [diseases] that for me have importance. Diseases are in principle, above all childhood diseases, infectious diseases and contact with them have importance, and if I suppress them, what's the effect? If I change the ecosystem, the health-system, what will happen?"

He argued that the unknown impact of interference with the balance of the disease "ecosystem" might have unforeseen, possibly severe repercussions for human health.

Dr. K was similarly skeptical of the public health goal of disease eradication, not necessarily because vaccination policies may be breeding unknown dangers, but because disease eradication may simply prove ineffective. In interview, after acknowledging the successful eradication of smallpox, she spoke critically of policies of eradication, a strategy which she described as only moderately successful:

"Some diseases can be eradicated, but in the end not much changes. Nature puts forth new diseases, and then once again a new vaccine has to be developed in order to fight it."

She gave the example of a study that examined the measles vaccine and to what extent its introduction was associated with the reduction in rates of encephalitis, a measles-associated complication. Although measles-related cases of encephalitis were practically eliminated, the total number of encephalitis cases remained unchanged; the same number of children were suffering from brain infections before and after the introduction of the vaccine, demonstrating according to Dr. K the "balance of nature".

These arguments, rather than looking at the effects of the disease experience at the individual level, focus on the potential benefits of disease at the level of the population, as well as the potential drawbacks of the eradication of those diseases. The basic wish to avoid intervention in a natural system, however, be it the individual body or the overall "ecosystem" of disease, remains consistent.

Avoidance of conventional medication

Several participants also spoke of the importance of avoiding conventional medical treatments generally, including not only vaccinations but also fever-suppressants and antibiotics. Such an approach is again not necessarily "alternative"; the negative effects of the overuse of antibiotics are widely recognized, and there are also significant voices within the medical community that promote the benefits of allowing fever to run its course under normal circumstances⁴³. Here, participants describe their wish to avoid such interventions as a part of their decision to refuse vaccination, in some cases combining relatively normative assertions with more alternative notions, including the holistic benefits of the disease experience described above, as well as the "origin" of disease and "symptom repression", both of which are linked by participants to homeopathic health concepts.

Participant E, for example, spoke of his faith in the importance of *Selbstheilungskräfte*, or "one's own ability to heal. Not to take everything so seriously and immediately smack it down with medications." Focus-group Participant 3 also spoke of this aspect, emphasizing the holistic inclusion of the non-material as well as the positive aspects of the disease experience, specifically fever:

"Basically I find that the psyche is very important, that it's always involved

43 For example Dr. Wolfgang Graninger, Director of the Division of Infectious Diseases and Tropical Medicine at Vienna General Hospital (*Allgemeines Krankenhaus* or *AKH*) describes fever as a healthy immune-reaction; the avoidance of fever-suppressants may under some circumstances reduce the length of illness according to several studies (Stehrer 2012).

somehow. Not always this battle with symptoms, immediately whip out the conventional medicine, but instead that one takes ones time and pays attention...that you shouldn't repress a fever right away with painkillers, that we don't think that's good, because [instead] the individual immune-system can start to do the work itself...that fever isn't always bad, that it's also good sometimes to just lets the fever be."

Participant F, who was particularly articulate on this topic, was emphatic about the importance of avoiding antibiotics and other conventional medical treatments, "because, in my experience, these treatments weaken the immune-system". To clarify what she meant, she told the following story:

"Once I went to a normal pediatrician, and it was terrible. [My son] had a few spots on his bottom, and [the doctor] didn't even ask, she just went ahead and smeared on an anti-fungal ointment. And in homeopathy, one says that where there's a symptom, and you just smear it away conventionally, then it's just going to come out somewhere else. That's it, this, seeing the person as a whole, and not as a symptom-carrier, so to say! Do you see what I mean? In this sense classical homeopathy is very strict."

She went on to talk about the commonness of the reductive focus on symptoms and resulting repression in today's society:

"Illnesses are pushed away, yeah, I have a little headache, so right away I take an aspirin. But what does it mean, headache? Why do I have a headache? Where does it come from, what's the origin?"

Participant D objected to conventional medical treatment on similar grounds:

"I'm not in favor of quick medication...if the kids have a fever, then lots of rest and lots of attention is important...I'm against immediate repression with medicine. On that day maybe it's better, but the origin of the problem goes untreated. Just the symptom is repressed...I just have the feeling that when, that when a child is sick, it should have fever, and then right away it's given fever tablets, and antibiotics, and it's a battle. And one does battle with the symptoms, so to say, but the origin of the illness isn't fought, and the body doesn't learn how to deal with it itself."

These statements combine the general wish to avoid over-medication with homeopathic concepts, according to which the "origin" (*Ursache*) of illness is a lack of holistic balance; as described by participants, treatments should target this imbalance, rather than reductively focusing on the repression of symptoms. By encouraging the self-healing process, such treatments help the individual to regain balance, a process that is seen as strengthening; if this

process is interrupted through conventional treatment, the imbalance remains, and this strengthening process is also interrupted, potentially resulting in weakness or even damage. Mrs. M also spoke of the danger posed by "robbing" the individual of the disease experience through treatment with conventional medication:

"With repression, you just break the body. You have to give the body a chance to heal itself. And with antibiotics, they're often prescribed because of a fever or a throat infection or something, and then once you've recovered [from the effects of the medication] it comes again, when the body is strong enough, and it's a positive sign when it comes. And people think that this is negative, because [the symptoms are] back yet again, and then again antibiotics. And the body simply has no chance to help itself."

According to this reasoning, homeopathic treatments are strengthening in that they help the individual regain holistic balance through their own powers to heal; conventional treatments, in contrast, are based on a reductive view that treats disease as mono-causal, targeting symptoms caused by bacterial or viral infection, for example, rather than holistic imbalance. This targeting of symptoms is seen to instead weaken the individual by halting the process of balance-restoration, or, put another way, by robbing the individual of the chance to grow in robustness through the disease experience, a process which is encouraged by homeopathic treatment.

Participant F spoke of her wish to strengthen her child's defenses with homeopathy in particular:

"Our mindset is that we want to improve our child's immune-system. And when he comes down with an illness, that he then, that with his body, and also his soul, essentially, that he can face it with his whole person and get healthy. And homeopathy supports you, it gives you, well let's say pushes in the right direction...homeopathic treatments [help to] improve the immune-system, helping it to become always better, always stronger, as time passes...What I really want, I want him to be an Augustin⁴⁴, you know? To be able to fall in the plague pit, and stay healthy. Yeah, it can happen! And that's the direction I'm striving towards."

Although most participants failed to speak of a direct link between symptom repression and the dangers of vaccination, the association of strength with the illness experience as well as weakness with treatment through conventional medication naturally problematizes the desirability of disease-avoidance through vaccines. A father at Dr. L's information session did

⁴⁴ Briefly, Marx Augustin was a 17th century Viennese balladeer, probably best known for the feat of sleeping off a drinking binge in an open grave full of the bodies of plague victims. As the story goes, he fell asleep in a ditch beside the road; mistaken for a corpse, he was collected and tossed in amongst the dead. He escaped the pit, uninfected, the following morning (Bramanti 2011:4).

imply a connection, saying:

"It's not that I'm against vaccination as a rule, but I've seen a lot of children who have been stuffed full of fever-suppressants and antibiotics and stuff like that much too early. I want my kid to have a strong immune-system, and really I'm worried that vaccination might interfere with that."

Participant D was more specific:

"Lots of people give fever suppressants to a child with a fever of 38 degrees. I would never do that...because the body needs to, fever is good anyway because the body fights the viruses itself. And I think it's the same thing with vaccinations. [Children] are pumped full of all these vaccines that might be helpful against this or that disease, and then the child gets another disease instead and becomes seriously ill because the body simply didn't learn to deal with such things itself. Because everything was just killed."

In short, regardless of the underlying logic, these participants believe in the strengthening value of the disease-experience, and suspect that over-use of conventional medications in general may interfere with this process. Vaccines are seen as yet another method of conventional medicine for avoiding an experience that is in fact beneficial to health.

Vaccination as violence

This storyline, which was only voiced explicitly by a single participant, reverses the previous arguments: just as the disease experience, including the suffering it entails, can be seen as strengthening and even character-building, so can the suffering that accompanies the vaccination experience be seen as potentially damaging, especially on a psychological and/or holistic level.

This issue was hinted at by Participant F, who spoke of a needle-related, non-vaccine intervention, the vitamin K injection, as a part of her vaccine refusal experience:

"It already started in the hospital. I wanted a home birth, but unfortunately it was an emergency cesarean, and the hospital pediatrician, he really lambasted us because we didn't want to give [our son] this vitamin K, immediately, you know? And he explained to me that my child will die of a brain hemorrhage if I don't give it to him, more or less...For me it's just another vaccination, this vitamin K."

Whether her primary objection to the vitamin K injection related to the nature of the injected material, or the injection itself, was unfortunately left unsaid. When asked if the needle was a factor for refusing vaccination in general, she hesitated:

"I mean, I have to be honest, with the injection [laughter]...I just don't need it. I mean, I wouldn't [vaccinate my child] if it was yummy candy, either, I still wouldn't vaccinate. But I don't know, I also don't understand it, why parents do that to their children. But it's like that."

As she described in the previous section, Participant F is convinced of the holistic value the disease experience, including the suffering it entails; the suffering induced by the needle, however, she implies is tantamount to abuse. She also expressed concerns about the psychological effects of vaccination, describing unvaccinated children she knows as "vital" with "heads of their own", in contrast to vaccinated children:

"It seems to me that vaccinated children are a bit dull-edged. Maybe that's just a prejudice, I don't know, but I have the feeling that they're oppressed by [the vaccination]...there's a theory that children are domesticated, basically, through vaccination. [Laughs] That these vaccinations basically fix children into a particular grid, after which they aren't able to live out their individuality."

In short, she (hesitantly) links the vaccination-intervention to psychological effects.

Participant J was more specific about the mechanism connecting vaccination with psychological damage. In order to illustrate the beginning of his critical stance towards vaccination, he also spoke of the refusal of a non-vaccination intervention; when the midwife in attendance at his daughter's home-birth tried to take a routine blood sample, what's known as a *Fersenstich* or heel-prick because it is drawn from the infant's heel, he and his partner refused; to him, the *Fersenstich* represented an intervention to be avoided the same as a vaccination, despite the complete lack of a chemical component.

Participant J was alone in explicitly elaborating on the violence of the injection itself as grounds of refusal:

"[Vaccination] is a rather aggressive act...And I'm sure there's a level... I'll sloppily call it the psychological... I'm not sure that these sorts of actions can't have an effect on people, in the sense of solidarity, directly or indirectly."

He was asked whether he meant that the vaccine substance itself could have a psychological effect.

"I'm not sure if it's the substance, or the act itself. Because it's really a violation. It's always a violation, whether intentional or unintentional."

He went on to describe how such an intervention can do psychological damage, "...because the young body says, whoa, they've done something to me, they've hurt me." He repeatedly

mentioned this thematic of the violent nature of the act of vaccination, and the possibility that such acts result in isolated, damaged people:

"...people who can't build attachments...which effects how people interact with their surroundings, their world, their home. A person who has experienced care and attachment probably can't chop down a hundred-year oak," in contrast to people who through aggressive treatment have lost touch with others and with their environment, "...people whose spirits have been broken. The earth won't be able to feed such people for long...like a mother goat who, constantly battered by her kid, finally says now I'm throwing you out the door."

This argument opposes vaccination specifically because of its perceived violence, pinpointing the suffering inherent to the act of vaccination as a potential source of psychological damage.

The natural disease experience is seen by certain participants not only as strengthening, but as beneficial to a child's holistic development. In contrast to the strengthening/character-building nature of the disease experience (including the suffering it entails), the act of vaccination (including non-vaccine needle interventions) is seen by key participants as potentially damaging on a psychological level, with one participant linking that damage specifically to the violent nature of the act, encapsulating both concerns with "naturalness" and non-intervention as well as holistic aspects.

Discussion

Participants who contributed to this section use a variety of logics and concepts, from conventional to distinctly alternative, to describe grounds for vaccination refusal which in certain respects point to the unspoken assumptions underlying vaccination policy. Participant insistence on the beneficial nature of certain disease experiences, for example, calls attention to the assumption that disease avoidance is universally desirable (and therefore always warrants medical intervention); participants also question the equally unspoken assumption that disease eradication can and should be thought of as a universal goal. Participants also point to the potential negative impacts of what are frequently framed as generally harmless and/or beneficial interventions, from the over-use of everyday medications (spoken of by a number of participants) to the needle-jab necessary for various interventions (which was addressed explicitly in only one interviews). Here, participants reject these assumptions on the basis of their own experiences, as well as in reference to the general uncertainties inherent to human interventions in complex systems.

In other respects, the arguments presented here can be seen as extended contributions to

other aspects of vaccine refusal described in previous pages. For example, the general desirability of certain diseases (specifically measles, mumps, and rubella) may well contribute to the overall perception that vaccination against these diseases isn't necessary, as presented in Chapter 3.2 (see "Risk of consequence", page 41). Several of these storylines also provide possible explanations for how vaccination might negatively impact the immune-system as described in Chapter 3.1., including the strengthening nature of certain disease experiences (which some participants described as being specifically beneficial to the immune-system) as well as the weakening effects of conventional medical treatment.

Many of the storylines presented here argue for the desirability of natural processes and experiences, and against artificial interference, whether that interference comes in the form of an eradication campaign or the intervening needle necessary to take a blood sample. There is an element of contemporary romanticism present in many of these arguments (regardless of their explicit or implicit links to alternative concepts) in which substances, experiences, and even forms of suffering are categorized according to their naturalness (which is seen to be positive/beneficial) and artificiality (which is seen to be negative/damaging). Vaccines, which can be seen as artificial both as substance and as intervention, may be serving as a nodal point for these types of concerns, combining suspicion surrounding man-made substances with concern about the effects of human interference on the natural world, including (but not limited to) the internal environment of our bodies.

Chapter 3.5 Individual responsibility

This chapter presents participant concerns and experiences which highlight the responsibilities of the individual in relation to health decisions. Although these storylines were rarely if ever cited as grounds to refuse vaccinations, they were nevertheless prominent in all aspects of the data set. They provide important information about participant values that are of particular relevance in this context, and contain concrete examples of how these values come into conflict with certain aspects of the vaccination promotion and delivery systems that participants have come into contact with.

The importance of active participation of the individual in health-decisions was frequently spoken of by participants as part of a general approach to health that extends beyond the context of the vaccination decision. The following focus-group discussion, for example, began as participants spoke of the need to justify their children's vaccination status to their extended families. Participant 3 described these interactions as at times tense and difficult, but also as providing an opportunity to broaden people's minds to the fact that it is indeed possible to actively participate in health decisions, which in this case includes rejecting professional medical advice:

"I have the feeling, that with certain relatives, it's a bit of an 'Aha, so you do it differently'. Actually the first time, that there are other possibilities...'Aha, you've got the courage to do that, aha', even just that the possibility exists, a bit of an opening in the other direction...to question a bit, the men in white, that it's not always so simple, that there are other ways, other strategies of dealing with [these decisions]."

Participant 1 responded:

"Yeah, I had that experience with my mother- sort of, let's say a rethinking of values. My mother talked about how she was simply happy that finally there was something with which one could fight these diseases. And they just accepted everything, just this simple 'finally we have this. Finally we can deal with these terrible things. One could never question it, do we do it or don't we, we were simply happy.' But today, it's different. Now one has other, well, one has a choice, more, somehow. And society still has to get used to it, that now we have choices, and also have to make these decisions ourselves. And it's probably easier for many, not to worry about it, and to let the decision be made by a higher authority, so to say."

Participant 3 agreed:

"I think this is an important development, on the example of pregnancy and birth, for example. Before, all children were born at home, and it was simply a sign of affluence, that one could [give birth] in a hospital, all this new knowledge, and anyone who gave birth at home, they were somehow poor, they couldn't afford it. And now we're taking a step back, we're saying this is not poor or ignorant or whatever, if one wants to have a baby at home, in fact it has advantages. And the hospital also has advantages and disadvantages. And today we have choices, we can choose in a way that wasn't possible for our mothers...and this is now a question for our society."

Overall, the focus-group discussion emphasized individual choice, as opposed to passive obedience, as a new, positive phenomenon.

For a number of participants, this (as they themselves describe it) new, active approach to health and healing is an important phenomenon with which they identify closely. Participant G also spoke of interactions with her parents, who put her under significant pressure to vaccinate her daughter,

"...because it used to be that you HAD to vaccinate. For example when I was small, vaccination was mandatory, and my mother simply thought that that's more important than having any sort of personal opinion, simply because she had never learned that it's even POSSIBLE to have one's own opinion."

Such passivity was also spoken of in relation to the current generation. Participant D complained about her husband's lack of participation in health decisions related to their children, which she described as representative of his generally passive approach to health, "...according to the motto, ask the doctor. And if he says so, then do it, if he says jump out the window, then do it. That's what my husband is for me!" Participant E used the phrase "Doctor as God" to describe what he sees as a passive approach to health in society, in which the "men in white" serve as indisputable authorities. Under this configuration, the patient is a purely passive recipient, and the doctor is active and in control: "I go to the doctor, and he heals me", as he phrased it. He described his own approach to health as more interactive and self-initiated, that healing for him is something active, not passive. He spoke very positively of vaccine-critical information from Switzerland, which he saw as relatively unbiased and differentiated compared to information generally available in Austria:

"They leave the actual decision up to the readers, let them come to their own conclusions. In Switzerland these sorts of dialogues are allowed, here you have to fight. The Swiss are just more critical, I think. They're raised to think for themselves."

Again he emphasizes the value he places on active, independent engagement with health decisions.

A father at Dr. L's information session spoke of the effort that goes along with active decision-making, in contrast to an easier, more passive approach:

"I mean, this doesn't apply to anyone in this room, but a lot of parents are simply too busy or not interested in informing themselves about all of this, so they go ahead and vaccinate, and they don't have to worry about it."

He contrasted the active involvement of parents present at the information session to the passive acceptance of medical authority and expert-provided knowledge demonstrated by compliant parents. Dr. L himself repeatedly emphasized the need to empower parents and encourage active participation in health decisions, both in interview and during his information session. For example, he said to parents at the beginning of his session, "keep in mind, this is a discussion round! If you've read a study, or you know more about something that I do, then please say it! I don't know everything!" He implies, like the above participants, that his status as a "man in white" doesn't give him indisputable authority, and encourages parents themselves to engage in the topic. He, like many participants, places significant value on the active engagement of individuals in health-decisions, which by nature must involve the evaluation of expert-provided knowledge.

Although, as described in previous sections, participant motivations for refusing vaccinations were in some respects highly varied, all agreed on the personal, individual nature of the vaccination decision. For example, according to Participant A:

"Really, everyone needs to make this decision themselves. I mean, the state can make its recommendations, of course it can, as long as it's really left to each mother and father to decide for themselves whether or not they do it."

or Participant B:

"At the end of the day, it comes down to one thing, that everyone has to make this decision for themselves."

Parents at both information sessions frequently claimed responsibility for their decision even as they inquired for information: "of course it's our decision, that much is clear to us!" smiled a mother at Dr. L's session. Even Participants F and J, who described themselves as entirely opposed to vaccination, made it clear that although they personally believe vaccination to be

harmful, the decision is still an individual one. When asked what he thought of the state-endorsed vaccine recommendations, Participant J said "everything is fine, as long as it's on a voluntary basis". Participant F insisted that she would never think badly of someone for choosing to vaccinate:

"I totally understand mothers, single moms for example, that just go ahead and vaccinate against everything. Everything, because I just can't manage, I can't take the responsibility, I don't have the time or the strength to stay home for six weeks with a sick kid...really, everyone needs to make this decision for themselves."

Participants were relatively consistent in emphasizing the importance of individual choice, and thus individual agency, over and above their own personal reason to refuse or accept any given vaccine.

Many participants spoke of the heavy responsibility this sort of active decision-making brings with it, especially in the context of parenthood. The focus group spent some time discussing this sense of responsibility; Participant 3 spoke of the self-imposed pressures involved:

"Vaccinate, don't vaccinate, these confrontations with the topic, the pressure that one makes on oneself...one can't be sure if this is the right way, and it's a lot of pressure!"

Participant 1 responded:

"Yes, all of the sudden, from today to tomorrow, you suddenly take on so much responsibility, for another being, and have to make all these major decisions...this is a huge responsibility, I think."

Participant F also spoke of the weight of responsibility:

"One can't just say, I'm not going to vaccinate, and just not go to the doctor, just like that. I mean, it's a huge responsibility, you have to be totally present every second, always know and feel exactly what needs to be done...and of course I worry about [my son]. Of course I do."

Dr. K placed similar emphasis of the serious nature of the decision not to vaccinate, as she described in interview:

"Where I'm always very aware and careful is with young parents who are very much in the contra-phase in terms of their psychological development, who want to be against everything, to be alternative, to be different. And I always say,

everyone must be able to argue exactly why they don't vaccinate. Just because it's chic, or because they're against it, I won't accept that. It's just too much responsibility that one has, and that one has to assume for the child."

In short, many participants emphasize both the value they place on active engagement in health decisions, as well as the serious nature of the responsibilities that go along with it. The personal nature of the decision to refuse (or accept) vaccinations places responsibility, heavily, on their shoulders; as participants describe it, it is not only the parent's right, but also their duty to make the best decision, as they see it, for their child.

Clinical experiences, positive and negative

Actual interactions with health-care practitioners in regards to vaccine-related issues were frequently described as problematic by participants. Accusations of irresponsibility are described as conflicting with participant self-conceptions as active and engaged parents; abrupt, rude or hurried treatment is described as offensive and/or as a block to information access, sometimes encouraging participants to look in a more alternative direction for vaccination advice. Participants also describe positive clinical experiences, which are characterized by open and non-judgemental discussion of vaccine-related issues.

Several participants spoke of clinical experiences that contradicted their conception of themselves as concerned, responsible, and engaged parents, describing interactions in which they felt accused of irresponsibility by health care providers for their choice not to vaccinate, or in certain cases for even considering vaccine refusal as an option. Focus-group Participant 2, for example, spoke of switching from a standard pediatrician to an alternative doctor because of vaccination issues:

"I mean, with this doctor, it very often came up during the consultation, how irresponsible we are, and I find that really out of line. Really trying to give us a bad conscience, that I'm a bad mother since I don't protect my child, basically. And I just think that there are plenty of parents who do vaccinate, not because they think about it and inform themselves and then decide okay, I'll vaccinate my child because for this-and-this reason, instead they vaccinate just because the doctor says now it's time, and then they do it. I mean, I find it much more aware and responsible to think how will we do this exactly, to really give it some thought, and then in some circumstances to decide against it."

Focus-group Participant 3 continued:

"I think this has another dimension to it too, if we as the mothers of our children are really irresponsible- because our children are so important to us that we give [these issues] so much thought, and then someone else comes along and says 'you, you're not paying attention!' or 'you're putting your child in danger' or whatever. Really, it's unbelievable."

Participant G also spoke of an uncomfortable clinical experience, in this case a hospital situation where her child's vaccination status became an issue, and she felt accused by a young doctor of being an irresponsible mother:

"She wanted to convince me that I'm irresponsible, that I'm who knows what. She had no idea. She can decide for herself however she wants, for her child, when she has one. She can tell me what she knows, she can ask questions. But NOT patronize me...about something that I've chosen to do very consciously...I just told her that if she wants to make her argument, if she would like to explain to me why she's of this opinion, I would be happy to listen. But I make the decision, my partner and I, along with the doctor we trust."

The value these participants place on the health of their children and their own decision-making autonomy conflicts with accusations of irresponsibility in clinical settings.

Accusations of irresponsibility at doctors clinics were also mentioned at both information sessions. A mother at Dr. L's session spoke angrily of being put under pressure by her pediatrician to vaccinate: "if I don't, then I'm a bad mother!". She cited this disrespectful treatment as motivating her to attend Dr. L's session. Another, more extreme example of such an interaction was given by a parent at Dr. K's information session, who spoke of being thrown out of a doctor's practice because she wanted to take some time to gather information before vaccinating her infant.

"The doctor told me he had no room in his practice for unvaccinated children. I mean, my daughter was 3 months old! He took me completely by surprise. All I wanted was information, and a bit of time to inform myself."

It was in part because of this abrupt treatment, she said, that she decided to attend the information session.

Several participants spoke in particular of uncomfortable interactions with receptionists; Participant G spoke of the experience of taking her daughter to a neighborhood doctor:

"It wasn't aggressive exactly, but [the receptionist], she said 'aha, we're not

vaccinated are we? But I'm sure you realize that Madame Doctor is a serious vaccination proponent!', really very snappy. The doctor herself, she just asked at the beginning, and just said 'Aha', and let it be. I mean, that was okay."

Even so, despite the fact that she had been hunting for a general practitioner who was conveniently located and accepted her insurance, Participant G decided not to return. Participant C received similar treatment by receptionists at her son's regular pediatrician:

"Every single time I went in there, it started up, already at the front desk, 'Oh! [Your son] still isn't vaccinated?!', and then the second receptionist, 'Goodness, no vaccination yet?'...it really annoyed me, every single time."

She described interactions with the doctor himself as primarily positive, emphasizing that he took a lot of time to discuss the pros and cons of vaccination with her, "a good doctor", as she described him. Still, after awhile, the constant pressure, which according to her description was coming primarily from reception, caused her to switch to a vaccine-critical pediatrician. "Really, it was just because of vaccination," she said. These experiences, as related by participants, indicate the delicate nature of the topic of vaccination, and the need of participants to be treated with respect in relation to vaccination refusal.

Participant A complained of rushed treatment and frustration at the lack of credible information provided by her pediatrician. She spent most of her pregnancy in the United Kingdom, and compared her clinical experiences there with her experiences in Vienna:

"I mean [in the UK], when you go to the doctor, they have time to work with, and you also hear critical information about vaccines. And that's pretty rare here...here the information is very one-sided...there things are discussed a lot more openly."

She spoke about the visit when her daughter received her one and only vaccination: "Yeah, the pediatrician was actually very, well, you're dealt with very quickly. You know, in, vaccine, bam, there, see you later." When asked if she was able to ask any questions about her concerns surrounding vaccination, she answered: "Eh, mm, yeah...he didn't seem to want to take the time. I mean, he really does it, like, on a conveyor belt." She said that although overall she finds her pediatrician to be competent, she's still actively looking for a more open, alternative pediatrician who will take the time to provide her with adequate information.

When participants spoke positively about their experiences with doctors, it was often to praise them for their willingness to discuss issues surrounding vaccination without judgment. Participant G, for example, finally found a homeopathic doctor she was happy with: "We've

been with her for 5 years now, and there's no criticism of what we're doing, but instead a very open basis for discussion." Such praise was not limited to alternative practitioners; both Participants D and I (as well as Participant C, as mentioned above) spoke of equally open-minded treatment from conventional pediatricians who were willing to take time to discuss vaccination issues with them. As Participant D put it,

"We discussed it for a while, and what I wanted to know, he told me, but he didn't judge. He didn't say you have to vaccinate, and he didn't say you don't need to vaccinate. But he gave me detailed information."

Participant I also praised her pediatrician:

"He says, 'you have no obligation, of course. This is my recommendation, and that's it. Informing, that's my thing, you have no obligation, how you decide'. And I think that's very appropriate."

Again, she emphasizes the importance of open discussion, combined with respect for her own ability to come to an informed decision. In short, these participants value respectful, conscientious treatment, as demonstrated by practitioners who take time to address their concerns; in contrast, accusations of irresponsibility, as well as rushed or hurried treatment, frustrate parent efforts to come to and then stand by their individual vaccination decision. Accusations of irresponsibility by clinical staff and/or hesitance on the part of the clinician to adequately inform conflicts with participant values emphasizing the importance of individual agency, in some cases driving them away from otherwise satisfactory health care professionals and towards vaccine-critical practitioners.

Insufficient information: barrier to choice?

A closely related issue that was frequently spoken of by participants was problems surrounding vaccine-related information access. Information in favor of vaccination was frequently described by participants as one-sided and/or partial, especially in regards to vaccine-associated risks. Again, the partial nature of information in favor of vaccination was described as frustrating parental efforts to inform themselves, in some cases encouraging participants to make use of more alternative sources that specifically address their concerns.

Several participants spoke in particular about the lack of acknowledgment of vaccine-related risks in available pro-vaccination information. Participant B spoke specifically about

information published online by the Ministry of Health, which she said she had read thoroughly:

"It seemed to me that yes they recommend [vaccination], say that it's very important, but they're purely pro. Which I understand, really. But information about [vaccine-associated] risks, it's too little, it's not even mentioned as an issue...One doesn't have to say vaccines are bad! That's utopian. It also doesn't need to be like that, vaccines have done a lot of good. But simply a bit more information. Because right now, the information that there is, is basically that your child will die if you don't [vaccinate]!"

Participant D wished specifically for more statistics about vaccine-associated risks:

"I just want to be told what CAN happen...no one says that actually, and I have no idea by how much of a percent, maybe it's almost as high [as disease-related complications], that something can happen because of the vaccination...it needs to be two-sided, the dangers of vaccination need to be shown, I think. So that one can then say, okay, which risk is less, what do I do?"

When asked about what she thought of the state's vaccine recommendations, Participant A answered with a similar wish for more comprehensive information:

"Yeah, you get these recommendations, but maybe one should also be informed more, as well. What, about the risks, not just the one side. That would be what I would wish for. I think a lot of parents are really confused. I often think, did I really make the right decision? It's complicated and difficult."

Participant H also spoke of the need for more information about vaccine-associated risks and other relevant issues:

"If I'm going to have an operation, even if it's an operation that almost always goes smoothly without complications, I'll still be informed about what can happen. Also with anesthesia, even if it's a really minor- they still have to tell me that in one out of 10,000 cases, I don't know, this or that happens. And with vaccination, this doesn't happen. And that's problematic, I find...the strength of effect should also be disclosed, so that parents really have some information about what [vaccination] actually does. How, how high is the risk of infection with vaccination, how is it without vaccination. And that's almost, I mean, you need to have access to scientific sources to get at this information, for example with haemophilus or some such thing. Being vaccinated doesn't mean you won't get it. It's simply a change in the risk [of infection], but to know that, you have to look in scientific journals. And that just can't be."

These participants speak of what they perceive of as a gap in the information provided by

conventional sources, which makes it difficult to come to an informed decision. Participant B described this information gap as again encouraging the use of alternative information sources:

"I think that people who want to get involved, they do it anyway, but the problem is they can't really get much information from the Austrian State, they have to get it from somewhere else, or they have to talk to alternative doctors."

Participant F made a similar comment:

"I mean, I had to go to really very unconventional people in order to find anyone who would communicate openly with me [about vaccination], and not just the usual, 'uh, your kid could get sick'...we want to be treated like responsible citizens, also about the risks of vaccination."

The focus-group discussion also placed special emphasis on the importance of enabling informed decision-making. Participant 2 spoke of this aspect:

"I mean, of course [vaccination is] not compulsory, but in a way it is...I mean, no doctor normally asks if you want to vaccinate, instead they say next time this and this will be vaccinated. And I just think there could be more information-"

Participant 3 interrupted:

"That's it, simple, unbiased information for parents, that still puts the responsibility in the hands of parents."

Participant G also spoke about the importance of access to information so that every parent who wishes to:

"...can establish their opinion. I'm not for screaming demonstrations for a particular point of view. I'm always of the opinion that people should be given the responsibility, um, I mean, be enabled to take responsibility. Because at the moment, the opposite is taking place."

These participants feel that the information provided by conventional sources ignores vaccine-related risks and other concerns of importance to them; several participants speak specifically of the need to make use of alternative, vaccine-critical resources in order to access information addressing these concerns.

Discussion

The importance of individual responsibility was a major theme within the data set, with significant mention in nine out of ten parental interviews and all other data sources. The emphasis of individualism as a key value resonates with other aspects of vaccination refusal, from the emphasis of the uniqueness of the individual child expressed in the discussions of vaccine safety (Ch 3.1) to the highly individualistic approach to risk-evaluation described in Chapter 3.2. In the present section the individual is once again foregrounded, not only as the focus of concern in regards to vaccine safety and/or necessity, but also as the locus of responsibility and decision-making.

The descriptions of both positive and negative clinical experiences as well as dissatisfaction with vaccine-related information shared here indicate that certain aspects of the vaccine delivery system are coming into conflict with key values held by participants, who see their own participation in health decisions, including but not limited to the decision to accept or refuse vaccinations, as an important element of their duties and responsibilities as parents. The importance of this particular form of individualism, in which one's own individual perspective is seen as the nodal point from which health decisions must be made (and thus expert-provided information evaluated), may be of key importance to understanding the concerns of many vaccine-refusing parents, bringing with it as it does issues of respect, autonomy, and the need for detailed information that many participants describe as highly valuable, and in some cases as highly lacking, in the context of vaccination delivery.

Chapter 3.6 Power and influence

This chapter presents participant concerns surrounding power and power relations in connection with vaccination policy. The "pharmaceuticals industry" serves as a key feature, with participants frequently linking the influence of industry to the promotion of vaccination by a variety of actors, from individual doctors to state-level decision-making bodies. These storylines were present in every interview in the data set, the focus-group, and both information sessions, and six out of ten interview participants (A, B, E, F, G and H) cited suspicions about the influence of industry as a primary reason to refuse vaccination.

Participant E, for example, spoke of the importance of such considerations for his choice to refuse vaccinations for his son:

"There I was with a baby, confronted with all this for the first time more or less...I had no idea before. You don't think about it for a second, and then all of the sudden, WOOP, vaccine schedule for newborns until the sixth year of life. And you take a peek inside. Matrix- whoa! There, and there, and there, WHOA! What's going on there?! I mean, how is it that we all managed to grow up? How did we survive, why are there so many people in our generation? That's when I started to really pay attention. My first thought, it wasn't concern about safety, but more that there's a system behind this...the political factor and the power factor play more of a role for me than side-effects, let's say...For me it's just not conclusive how all this happens, always more financed vaccine-types, always more recommendations- where is it all headed? There's really a lot of panic being made, don't you think? As if a massive pandemic is standing at the door...and my basic concerns are, that there's a lot of money-making behind all this."

For him, the role of the economic interests backing the production of vaccines cause him to be suspicious of vaccination policy.

Similarly, when asked if she refused vaccination out of fear of vaccine-damage, Participant G answered, "Risk of vaccine-damages? Ahem, skepticism towards a profit-driven society, more like." She also pointed to the vaccination schedule as evidence of interference:

"[The schedule] is constantly growing. I mean, just in the time since [my daughter] was born, when she was small it was still, at that time they switched from the 4-component to the 6-component vaccine. And now there are even more vaccines [on the schedule], and even more."

She spoke more generally of "dangerous linkages" between economy, science and politics, specifically in relation to public health:

"What really frightened me, is really, there is very good research to read about how economy, science and politics function, and the links between these three elements. If you look at it from a critical perspective, it's really terrible, I find."

She spoke in particular of Martin Hirte's book *Impfen Pro und Kontra* (2008), which focuses on German vaccination policy:

"...that was so shocking for me, that it was a very strong reason not to vaccinate [my daughter], at least not yet. She was still so small, and the results I read, that was the book where I came across the opinion that it's these connections, between economic interest, politics, and public health, that are so dangerous. In concrete terms, I can't name the people currently in Austria, in the sciences or business or politics, who are making these decisions. But unfortunately I would assume that it works like that here, too."

When asked if her refusal had to do with vaccine-damage, Participant B also spoke of the influence of industry over vaccine policy:

"I just think that [vaccine-damages] are often not talked about, that it's kept under wraps. I mean, I don't want to assume anything. But the pharmaceuticals industry just has more money and more power. And I'm just not sure what is being marketed versus what's really necessary."

Each of these participants link their own refusal to the influence of economic interest over vaccine policy, which is linked to belief in the dominance of these interests over other actors within medicine, the sciences, and the state.

A number of participants spoke generally about resisting the "fear-lobby", through which industry (and other subordinate actors, such as physicians) encourages the passive consumption of pharmaceuticals and the constant expansion of the vaccination recommendations, thus influencing the general behavior of the population. Participant F, for example, cited such "fear-mongering" as a major reason to reject vaccines:

"I just don't like how pharmaceuticals firms, and also doctors, how they work with fear. The argument for vaccination is fear...what the doctor showed me, it was a promotional brochure from the pharmaceuticals industry for vaccination. And it costs, they're earning huge amounts with [vaccines]. Huge. And I mean, all these stories, all the flu-vaccines, chicken-flu, what was that? First the chicken-flu, and then the bird-flu, or the other way around? And then some other flu? And then the state, I mean, yeah- it's really just fear-mongering."

Focus-group participant 3 spoke of the importance of this aspect for her decision:

"For me an important point is that the pharmaceuticals industry simply, that all this consumption and safety-thinking, that consumption, that there's a logic behind it, that it's being used to make a profit, in a very manipulative way. Fear-inducing, that we parents need to watch out for our children, and the doctors are always trying to give you a bad conscience-

Focus-group participant 1 interrupted:

"Yeah...you're sort of the boogie-man if you don't vaccinate! You're putting the poor children in danger, and it's not even publicly discussed, this very strong opinion, that we need vaccinations, that vaccinations are so important, and in my opinion this is all supported by the pharmaceuticals industry and economic considerations, and there it all goes downhill, because it's just not reflected upon, as a societal phenomenon."

Phrases like "panic-making" and "the fear-lobby" were used frequently by participants.

Participant D, for example, spoke about fear in relation to the FSME vaccine (which she says she will most likely give to her daughter):

"Through the media, this panic-making, this fear-mongering. And these pictures that one sees, a totally healthy person, the attack from behind, a tick, and BAM, it's over!"

Participant F was more vehement:

"I find all this tick-advertising to be an effrontery. An EFFRONTERY. They're just playing with our fears."

All these participants are pointing to the influence of industry on various aspects of vaccination, from general influence over science and medicine to aspects of control exercised through fear-based promotion of vaccines, whether through advertising campaigns or individual doctors; in any case, these participants are linking a variety of actions, from the decisions of policy-makers to recommend specific vaccines to the vaccine-promoting conversations taking place in individual doctor's practices, to the influence of industry, the primary motivation of which is not to promote the health of children, but to turn a profit.

Mechanisms of influence

Some participants spoke more specifically about the "links" through which industry enacts its power over medicine, science, and the state. Three different mechanisms through which the

economic interests of the pharmaceuticals industry are promoted were described by participants: bribery of individual doctors and other methods of monetary "encouragement" of vaccination promotion; the suppression of scientific studies questioning vaccine safety, necessity or efficacy; and the infiltration of policy-making bodies.

Some participants suspect that the pharmaceuticals industry uses its economic resources to influence the behavior of medical professionals, directly through straightforward bribery or more indirectly through political pressure. Participant A, for instance, described her own hesitance to trust medical personnel:

"The doctors, I think, they're just not honest enough. I mean naturally, they work together with the pharmaceuticals industry, more or less. Everything, it's so one-sided, I think, what one hears about vaccines. So officially, yeah, this and that has to be, and it's all so safe, and, yeah, I'm skeptical."

Participant E shared her skepticism about the honesty of medical professionals:

"It's about money, billions, a lot of dough, okay? The pharma-giants indoctrinate the doctors, some of them are probably bribed, I'm 100% certain, the economy works like that. That means there are doctors, leaders of opinion, who then go to the media, and then, this whole bird-flu craziness? It's all on the same track...I'm not saying that everyone is being bribed by pharma, but I mean, it's economy, they're the ones with the power, and politicians are only conditionally powerful, you know? Let's just say, this is a political machine, steered by powerful interests. There's just so much money behind it...Where the ruble rolls, the rules are decided."

Again, his statement emphasizes the relatively weak position of medical and political actors in relation to economic forces. Participant H spoke of his own experiences with what amounts to bribery in the health industry, also speaking of the dominance of industry over the state:

"Many trillions of Euro or Dollar are in circulation. And most people who advise aren't so personally wealthy that they're immune to gifts from pharma-firms! I have enough friends in the hospital industry, I know what kind of sums we're talking about. A friend of mine, for example, was offered a position, 3,000 EUR a month, and he didn't have to do anything...in this case it was a medical engineering firm. All he had to do was promote their products. Nothing more, he didn't have to work for it. And maybe that's a very crass example...but the expectation that a state could really manage to take a fair position, that said we stand behind vaccine-critical information just as we stand behind pro-vaccine information, it's just totally unrealistic. Because there's always lobbyism in one form or another."

For these participants, the possibility of bribery, whether direct or indirect, problematizes the trustworthiness of a number of actors, from individual doctors to vaccination policy-makers.

Another mechanism spoken of was the suppression of studies whose results are at variance with vaccine-promotion. Participant H, for example, again used an example from his professional life to illustrate his suspicions:

"You just have to look at the studies, how are the studies that help vaccination, epidemiological, and studies that show vaccine-damages. And in that case I'm simply very wary, because it's much more difficult to find studies that indicate vaccine-damage...I mean, I've talked to a lot of doctors and medical students over the years, and the topic is treated in such a one-sided way by medical school, that I'm just very wary...I know of studies that have been suppressed, because they, because the pharma lobby is behind it...I know someone, he was at a congress, and there was a presentation, in that case it was about nutritional supplements and vitamins and zinc that could replace a very expensive medication for a number of conditions, and this presentation was simply left out of the congress-report. That's what I mean by suppressed!"

Dr. K also spoke of her suspicion that vaccine-critical studies and information are being suppressed due to economic interest. During her information session, she explained to parents that the recommended frequency for certain vaccinations is excessive:

"In some cases, such as hepatitis B and FSME, the vaccine provides much longer immunity than the booster-regimen would imply. I always recommend a titer count⁴⁵ before refreshing these vaccinations. But studies that indicate this seem to pop up and then disappear again."

She hinted that this information, which would of course be relevant to the consumer, is being actively withheld. In interview, she spoke more of her concerns, emphasizing not only the influence of industry but also the willingness within the medical community to ignore any information that might support vaccine criticism:

"[Any connection between vaccines and the diseases of civilization] are simply negated by conventional medicine. You don't hear about it or read about it. Interestingly enough, you do read that childhood diabetes has increased in the last decades, or that autoimmune diseases have increased dramatically, and one doesn't know why, and studies that wish to demonstrate a connection aren't taken seriously, disappear quickly. It's also not in the interest of the pharmaceuticals industry. Of course they want to sell their vaccines, that's totally clear."

She emphasizes both the influence of industry, as well as hesitance on the part of the medical community to recognize evidence supporting any sort of vaccine-critical stance.

⁴⁵ A titer count is a simple blood test used to verify immunity through the presence of specific antibodies in the blood, as described in interview by Dr. K.

The Austrian Vaccine Commission (*Impfauusschuss*), which was at the time of research responsible for designing the state-recommended vaccination schedule⁴⁶, was also a target for suspicion regarding the influence of industry, with particular focus on localized interests represented by the FSME vaccine. Participant G, for example, suspected that the Commission is compromised:

"I'm not only of the opinion that a lot of [vaccination policy represents] a very dangerous connection between industrial and commercial interests, bloody so-called research, from the books I've read I know that there are close relationships, or at least close relationships exist, that are actually improper, that people, political people sitting on the vaccine commission, that determine the vaccine recommendations, who are actually economically involved with companies that sell vaccines. Or things like that....on the typical example, at least in Austria, of the tick-vaccine. From what I've read, the obvious conclusion is that there's simply an especially massive industry lobby [behind the recommendation of the FSME vaccine]."

Participant B also suspected that the FSME vaccine is pushed in Austria owing to local interests :

"I found out that [the FSME vaccine] is forbidden until 12 years old in Germany, the tick-vaccine, that it can actually have severe side-effects, and for that reason in Germany it's only allowed after 12 years. And in Austria it's only [recommended] because apparently an Austrian developed it."

Although she had had her son selectively vaccinated against FSME, she said she would think twice about doing it again owing to these considerations.

Participant H also expressed specific concerns about the representation of local interests within the Vaccine Commission:

"And then of course there are very specific, such as for example the Austrian FSME vaccine, where as far as I know for many years the license holder was sitting on the Vaccine Commission...and I know that there's a vaccine in Germany that's apparently far less irritating, but that is almost unused in Austria, you have to special-order it from Germany. And the license for the one from here is owned by an Austrian. That's one thing. And, I mean, FSME, that's an example, that's really an issue of money. As far as I know, from what I've read, there have been no documented cases of FSME before puberty. And that poses the question, maybe FSME is something that can't happen to an immature immune-system. And that poses the question, if the schools, if FSME should be vaccinated against."

Participant H, by this description, wonders if there is any basis beyond economic interest for

46 See footnote 15, page 11.

the recommendation of the FSME vaccine in childhood, and links the early recommendation to the presence of an individual with specific interest in the promotion of the FSME vaccine on the Vaccine Commission.

A father at Dr. K's information session asked why the FSME vaccine is so heavily promoted in Austria, and at such a young age, in comparison to other countries; Dr. K explained that Austria is an endemic area, to a greater degree even than neighboring countries such as Switzerland and Germany, but then added that that doesn't mean economic interest isn't playing a role. In interview, she spoke in particular of the Vaccine Commission in Germany:

"There are often double-staffing issues unfortunately, above all in Germany I know of individuals sitting on the Vaccine Commission who are employed by pharma firms. Which means the ethics are also not irreproachable."

In short, these participants suspect the neutrality of the individuals sitting on the Vaccine Commission itself, which in turn requires that the recommendations of such a commission be regarded as suspect.

The power of the Austrian Medical Association

A final mechanism frequently referred to by participants has to do with the disciplinary role of the Austrian Medical Association (*Ärzttekammer*) as a means of repressing or ultimately silencing dissenting opinions within the medical community. Participant F, for example, when asked about her primary reason to refuse vaccination, ticked off a whole list of factors, but her initial reaction was:

"I know doctors, I can't say their names, because the pharmaceuticals industry is so strong, apparently, that they can saw doctors down, more or less. *Zzz-zzz-zzz!*"

Participant G was particularly worried that the disciplinary power exercised by the Medical Association in the form of the revocation of medical licenses threatens the freedom of doctors to adequately inform their patients:

"It's like this, I know of a number of cases, also according to emails that I've been sent, that doctors that publicly give vaccine-critical recommendations have their licenses revoked. And that's a huge subject all by itself that I find very very important. That, that by, it would really interest me how the constitutionality-

there's freedom of speech in Austria, and there's freedom of assembly and freedom of the press, and yet the Medical Association, with backup from the pharmaceuticals industry, has so much power in Austria that they can revoke a person's medical license permanently. That means that this person's existence is threatened, and their family's. That means that this conversation that we're having now would be forbidden in a semi-public setting."

She spoke in particular of Dr. K (whose vaccine-information session she had attended in the past) as intimidated by the threat of disciplinary action:

"She tried to make [her presentation] as balanced as possible, since otherwise she'll be stripped of the right to practice...She knows that she consciously can't recommend specific literature at her session or use specific formulations, resigned to it, and because she's too afraid, she doesn't do it, simply because she wants to keep her practice. I mean, it's very extreme."

Participant H was equally critical of the disciplinary role of the Medical Association, which he sees as creating a barrier to information-access:

"The Medical Association says that anyone, and I heard this from two different doctors, that they've made it clear that anyone who gives vaccine-critical recommendations is not practicing legitimately, and can face penalties, can even be stripped of their license. From my perspective, there's just no informed scientific foundation for that. It just isn't right."

He was asked if he thought this made it difficult for doctors to share information with patients.

"Absolutely. They're risking their career. Not to mention liability questions...I mean if you were a doctor you'd have to think it over. Vaccine-critical doctors are, have much more of a risk, actually to fulfill their professional duties. And that, I find that highly questionable legally. It's bad health-politics. Because it has to be that one can access various sources of information. For me that's almost the most important thing, I have to say."

Both Participants G and H point specifically to disciplinary action within the medical community itself as creating a barrier for access to vaccine-critical information, although only Participant G links such actions directly and specifically to the involvement of industry.

When asked if she feared for her medical license given her vaccine-critical stance, Dr. K answered in the negative:

"No, because I'm not doing anything illegitimate. I'm very careful to keep myself

informed legally. I don't have to give every vaccine. I can go my own way...As doctors we're required to recommend all vaccinations, ethically. By doing otherwise I'm taking a position that goes against the 'state of the art'. [I've heard that] it can happen, through the Vaccine Commission or pro-vaccination colleagues, that doctors who don't give all vaccines can be denounced for negligence. And that worries us doctors, too, many are afraid. But if you inform yourself, from the legal side, it becomes apparent that it isn't correct, I can't be denounced for negligence, or for child abuse. I read in the *Ärztezeitung*⁴⁷ that we could be accused of child abuse for withholding vaccination, not true. But these are big, scary words, and they don't miss their mark."

She spoke of Dr. Loibner, the one Austrian physician who has actually been stripped of his right to practice owing to his stance on vaccination⁴⁸:

"He was very active, and created a lot of movement...but I also think that Loibner's behavior was frequently clumsy, and very provocative, and because of that his license was revoked."

Dr. L felt otherwise; although he also said that he felt secure that his own medical license was not in jeopardy, he denounced the disciplinary proceedings against Dr. Loibner:

"It was certainly a political decision...political and ideological. One wants to hold up a warning sign that others, but really they shot themselves in the foot, because to forbid a person for his opinion, for saying his thing so to say, and to have no opposing arguments in my mind, instead they just say (slipping into a heavy Viennese accent) 'we do it this way, so YOU have to do it this way TOO.' It's, yeah, one could almost say fascist."

Mrs. M also referred to the proceedings against Loibner as "political", describing the disciplinary commission⁴⁹ that heard his case as a "leftover from the Nazi-period", and their decision as utterly unjustified:

"A doctor can't be stripped of his license because of his opinion! We're not in Russia, after all! [All the other vaccine-critical doctors] are silent now, they don't dare to say anything. They have practices, families, loans, they can't afford it, to be denied the right to practice. It's a scandal."

These participants see disciplinary action directed at vaccine-critical doctors as problematic to varying degrees; all however emphasize the importance of the individual doctor's right to a non-mainstream opinion, especially in relation to the individual consumer's need for access to varied sources of information. They are particularly critical of the role of the medical

47 The Austrian Physicians' Journal: see <http://www.aerztezeitung.at/>.

48 His license has since been restored by the Austrian Supreme Administrative Court; see footnote 29, page 14.

49 The *Ehrenrat*, <http://www.aerztekammer.at/ehrenrat>, accessed 19.6.2013.

community, with the backing of the pharmaceuticals industry, in providing a barrier to information access through disciplinary action.

Discussion

Participants expressed concern that vaccination policy and promotion, including not only the state-promoted vaccination program but also the generally pro-vaccination stance of many medical professionals, may be linked to varying degrees with the interests of certain powerful actors, in particular the pharmaceuticals industry. These storylines frequently emphasize the agency of business interests while discounting or ignoring the independent agency of specialists, policy-makers, individual doctors, and other actors involved in vaccine promotion and delivery; these actors are frequently portrayed as "the pawns of pharma", much as refusing parents are frequently portrayed as "the pawns of the anti-vaccination movement" by those same specialists and policy-makers (Blume 2006). Just as those specialists and policy-makers, according to Blume's criticism, may be overestimating the actual impact of anti-vaccination activism on parental decision-making, so too may these participants be overestimating the influence of business interests on vaccine policy. It would be markedly naïve, on the other hand, to categorically reject these assertions.

However, regardless of their validity, the power-related storylines discussed here interact with other aspects of vaccination refusal in ways suggesting that they may be functioning not only as direct criticism of the societal-level influence of economic interest, but also as an explanatory model for other aspects relevant to vaccine refusal. This functions at at least two levels. First, the overriding power of economic interest provides a relatively simple explanation for the dissonance between the understandings of vaccine safety, necessity and/or efficacy discussed by participants in this chapter and "expert" explanations of these same phenomena; second, these stories also help to explain the environment of whole-sale vaccine promotion encountered by participants, both in terms of the behavior of health-care providers and available vaccine-information, as described by in participants in relation to *individual responsibility*. Participant descriptions of *individual responsibility* and *power* places similar emphasis on the importance of individual autonomy, the one in terms of the freedom of individual parents to decide for their children as they see fit, the other in terms of the freedom of doctors to share vaccine-critical information with their patients, as well as the general emphasis placed on the critical evaluation of expert-provided information, including evaluation of the motivating forces potentially influencing those same experts. Thus the

popularity of these storylines within the data set may be seen as a genuine criticism of aspects of the status-quo, as an explanatory model for other aspects of vaccine refusal, and as an expression of individualist values.

IV.

DISCUSSION

The goal of this study has been to examine the emic grounds for parental vaccination refusal within a specific social context. As presented in Chapter 1, such acts of refusal are best understood in relation to "local vaccination cultures", created through the social sharing of experiences with and ideas about vaccines and local systems of vaccine delivery (Streefland 2001, Streefland et al 1999). Eight discrete aspects relevant to vaccine refusal in this particular context have been identified and discussed: *immune-system concerns*, *vaccine-damage*, *risk balance*, *uncertain efficacy*, *the hygiene argument*, *alternative concepts and values*, *individual responsibility*, and *power*. Within this broad-ranging and diverse collection of ideas, stories and experiences, certain elements stand out as particularly relevant to parent concerns, especially in relation to vaccine safety, vaccine necessity and risk, the importance of alternative (and not so alternative) concepts, and the prominence of individualist values. Taken together, these conclusions are relevant within the broader discussion of the phenomenon of vaccination refusal, with specific implications for both clinical practice and vaccine policy.

Concern with vaccine safety was emphasized by most participants and is clearly highly relevant to the refusal of vaccines, in relation to two primary factors. First of all, discussions of vaccine safety (as well as closely related concerns surrounding *uncertain efficacy*) were often characterized by the emphasis of uncertainty. When participants spoke about the safety of vaccines, they were frequently explicit about the fact that many of the links between vaccines and negative effects are uncertain, and in some cases difficult (if not impossible) to prove. However, whether specific concerns focused on the effects of vaccination on the developing *immune-system* (which was heavily emphasized in the data set, and was often linked to concern with combination vaccines, especially the 6-component vaccine currently recommended in Austria) or to the possibility of serious *vaccine-damage* (which was spoken of as important by a minority of participants), this uncertainty fails to discount these concerns in the minds of participants. The second common feature is the relevance of age; babies and younger children were often described as being more vulnerable to negative vaccine effects than older children or adults.

Among the most striking aspects of the data set, however, was the discussion of *risk*

balance, which was dominated by the nearly unanimous assertion that *specific* vaccines are in fact not necessary and therefore warrant refusal. Most participants did not dismiss vaccine necessity entirely; their arguments focused instead on individual diseases which, from the perspective of participants, fail to present a risk serious enough to justify the use of vaccines. As in other areas of the data set, there was certainly an amount of false information circulating in these pages; it is however important to acknowledge that there is also a fair amount of *correct* information being used by participants. What their arguments make clear is that for participants who were categorically open to vaccination (as the majority of participants were, based on vaccination behavior as well as discussions of "exceptions" such as tetanus, FSME, travel vaccinations, and age-relevant vaccinations), perceived personal risk seems to be an important factor, and in some cases may be key to vaccine acceptance. In contrast, the relevance of epidemiological risk, and especially the maintenance of herd immunity, was simply not acknowledged, or, as demonstrated by the *hygiene argument*, was actively denied. In short, it is clear that many participants are actively evaluating risks during the decision-making process, with personal risk being weighted far more heavily than epidemiological risk; in fact, perception of individual risk in relation to disease may in some cases override concerns about uncertain safety, especially in respect to older children, for whom the negative effects of vaccination are perceived to be less relevant.

Alternative concepts, as well as advice from alternative health practitioners, were also spoken of as relevant, and clearly contribute to perceptions of safety, necessity and efficacy. However, it is important to point out that although alternative health concepts were spoken of by a number of participants, it is impossible to draw a clear line distinguishing "alternative" ideas from more mainstream concerns. Homeopathic resistance to conventional treatments bleeds into the general wish to avoid over-medication; and while one participant links ideas about the beneficial nature of certain disease experiences to anthroposophic teachings, another instead connects these same benefits to the co-evolution of mammals and disease pathogens. What did come through in participant arguments (regardless of the influence of alternative concepts) is that the values promoted by the vaccination-system itself, which include the goals of eradication established and promoted by the World Health Organization and other global actors, are not necessarily shared by individual parents, and that such discrepancies can encourage vaccination refusal.

Finally, the data set was overwhelmingly characterized by the emphasis of individualist values, not only in terms of the foregrounding of personal risk (and the problematization of communal risk), but also in terms of discussions of *individual responsibility*. Participants were

nearly unanimous in emphasizing their duty as parents to make well-informed decisions with regards to medical interventions, including (but not limited to) vaccination. Descriptions of interactions with the vaccine-delivery system were largely negative; aspects of the system, specifically disrespectful or hurried treatment by clinical staff and/or a lack of detailed information about vaccines, were frequently cited as barriers to active choice. Participants in turn linked these phenomena to issues of *power*, by which vaccination promotion (including the lack of discussion of such topics as vaccine safety) is ascribed to the influence of economic interest. Participant frustration at the unwillingness and/or inability of health care professionals to provide satisfactory information indicates that communication between practitioners and patients is failing in key ways. In comparison, alternative practitioners (as well as certain conventional practitioners) were praised for their open, non-judgmental treatment and advice, and there were several reports of transfer to alternative care or attendance of vaccine-critical information sessions in response to brusque/disrespectful treatment and/or as part of the search for credible information. This indicates that vaccine-critical, alternative practitioners may be attractive not only because of their "alternative" specializations, but also because of their willingness to cater to individualist values, including explicit dedication to the encouragement and support of autonomous decision-making.

These conclusions are by and large in agreement with much of the literature on vaccination skepticism and refusal, with certain key insights. As discussed in the introduction⁵⁰, parental vaccine refusal in Austria (as well as in other contexts) is often attributed by vaccine and public health specialists to the epidemiological transition, according to which the disappearance of vaccine-preventable diseases has caused parental concern to shift from those diseases to (primarily irrational) fears of side-effects. The results of this study certainly do indicate that fear of side-effects constitutes a significant element of vaccine refusal; however, these results also indicate that individual parents are not simply failing to understand the "real" risks of vaccination and/or vaccine-preventable disease. Most participants *included* risk-calculations in their evaluation of the desirability of vaccines; however, other modes of reasoning, from the relevance of unquantifiable uncertainty to alternative concepts and/or discrepancies in values, were also of significant relevance to their decisions.

This conclusion agrees with several social-scientific examinations of the topic, according to which the exclusive focus on risk and (false) risk assessment is based on the faulty assumption that risk is by nature objective and quantifiable (Blume 2006:40), resulting in

⁵⁰ See Chapter 1, page 12.

what has been widely critiqued within the social sciences/science studies as the “deficit model”. According to this view, dominant in the 1950s and 60s but far from absent today, science is “authoritative, objective, and universal” (Leach & Fairhead 2007:23), and any public objections to technologies or policies based on state-of-the-art scientific research are to be blamed on a knowledge deficit on the part of that public. Leach and Fairhead go on to explore the concept of risk, which according to Ulrich Beck (author of *Risk Society*) and others is only one conceptual frame for understanding danger in an uncertain world, a frame which may or may not be utilized by individual actors. The presumption that epidemiologically-determined risk has, or should have, “an objective and universal public meaning” ignores the fact that risk-statistics themselves are to some degree socially constructed, attempting to bring order to an uncertain world by making the “incalculable calculable” (Leach & Fairhead 2007:27). This leads to the tendency to ignore parental concerns that may be framed in other ways, for example in terms of unquantifiable uncertainty rather than quantifiable risk.

In her article “Understanding vaccination resistance: moving beyond risk”, Pru Hobson-West explores this thematic further, calling into question the basic assumption that “individuals make decisions about vaccination through a comparison of *risk*...[and] that any public resistance can be explained as a miscalculation of risk” (Hobson-West 2003:276). She deconstructs this approach, which she says contradicts itself in key ways. The idea that an individual with access to ‘correct’ information will analyze that information in terms of personal risk conforms to the rational actor model, with its focus on the individual; however, mass-vaccination policy is built upon the scientific concept of ‘herd immunity’, which is clearly social/communal in nature in that (minimal) individual risks are seen to be outweighed by the overall net gain in population-level immunity. She argues that if we do indeed live in a de-traditionalist society, in which individuals can be expected to behave as “risk-minimizing-autonomous-rational-consumers”, then the decision to refuse vaccination can be seen as entirely rational, in that it makes sense to “free-ride” and avoid the risks of vaccination while enjoying the benefits of her immunity. “This is an extension of Rogers and Pilgrim’s (1995) suggestion that in a society which currently promotes health by focusing on lifestyle and individual action, it is vaccination policy, and not the dissenting parents, that should be seen as the anomaly” (Hobson-West 2003:277). She goes on to discuss the general perception of uncertainty, which, like Leach and Fairhead, Hobson-West sees as an alternative way to frame vaccine-concerns, in which “unknowable unknowns” (such as the long-term evolutionary consequences of vaccines on human health) make it difficult, if not impossible, for

comparisons of risk, as "such unknowns would clearly be difficult to factor in, no matter how much risk assessment is carried out" (Hobson-West 2003:279). She suggested that parental concerns may more often stem from alternative understandings of health and disease (on the example of homeopathy and certain religious groups) than on the risk-avoidance model (Hobson-West 2003:278-279).

The results of this report indicate that in fact any given parent may be making use of any or even all of these various frames, *including but not limited to* risk-evaluation, in order to come to a decision. Many of the participants in this study, by their own descriptions, *are* in fact behaving as autonomous-rationalist-consumers, whose strict selection of vaccines is based on the perceived risks posed to the individual child (to the exclusion of communal considerations); they are also thinking in terms of more generalized uncertainties surrounding safety and efficacy which are difficult to address through risk-analysis; and they are taking other ideas about health into account as well, often including the influence of healing traditions other than conventional medicine. But most importantly, regardless of the particular set of frames from which vaccination is viewed, the parents who participated in this study were unanimous in asserting their right as rational, competent and above all responsible individuals to make decisions, as they see fit, for their children, and that their experiences with the vaccine delivery system, instead of enabling such decisions, in effect pose a barrier to informed individual choice.

The connection between experiences with the vaccination system and vaccine acceptance and refusal is widely supported in the literature. A positive relationship between trust in healthcare providers and the decision to accept vaccination has been indicated by a number of studies, including Moran and colleagues' pan-European focus group study (Moran et al 2008:16), as well as preliminary findings of the *Vienna Vaccine Safety Initiative* survey, which indicate that "parents who are satisfied with the relationship to their physician and those who are satisfied with the information they receive are most likely to be compliant with recommended vaccines"⁵¹. The converse, that a lack of trust in or negative experiences with medical providers can negatively influence vaccine uptake, has also been demonstrated by qualitative studies, especially in relation to negative clinical encounters characterized by busy nurses, rushed visits, and/or a lack of credible information (Luthy et al 2010, Tarrant & Gregory 2003). Honest and direct provider-patient communication, combined with the availability of sufficient information, is seen to be key to addressing parental concerns in

51 This quote is taken from the summary of Stephanie Helfert's 2010 unpublished master's thesis available on the VIVI website: <http://vi-vi.mobi/publications/2012> (accessed 29.7.2013).

regard to both vaccine safety and necessity (Luthy 2010; Moran et al 2008; Frederickson et al 2004; Nelson 2004; Balinska 2003 & 2004; Tarrant & Gregory 2003). A recent issue of the Austrian pediatrics journal *Pädiatrie & Pädologie* also included five articles addressing the phenomenon of vaccination uncertainty, skepticism, and refusal in the context of the clinical encounter⁵². "As valuable as vaccines are," writes the Austrian vaccination specialist Dr. Martin Haditsch, "worries and fears of concerned parties should be taken seriously within the framework of vaccination counseling, and should be discussed fairly and openly" (Haditsch 2010:20). The behavior of medical professionals, as well as the vaccine-related information they are able to offer, has the potential to influence vaccination acceptance both positively and negatively; the results of this study indicate a potentially serious breakdown in doctor-patient communication which compromises the effectiveness of "vaccination-counseling", and which may in some cases inspire concerned parents to turn to alternative, and frequently vaccine-critical, sources of advice.

The move away from passive obedience of medical authority and towards the active evaluation of authoritative knowledge on the part of the consumer has come to be associated with good parenting on a number of levels (Kaufman 2010:23), and the connection between vaccine skepticism, alternative medicine, and the contemporary move towards informed choice has also been made in a variety of contexts (for example, Kata 2010, Kaufman 2010, Wu et al 2008, Peterson and Lupton 1996, Rogers and Pilgrim 1995). This particular analysis supports these connections, and links this constellation of associations to the far-from-alternative value of individualism, which in many ways is more fundamental to the arguments against vaccination than any "alternative" constructs.

Implications for clinical practice and vaccine policy

As described in the previous pages, participants in this study place a large degree of value on their own agency and responsibility in the context of health decisions; the stories they tell about clinical interactions and dissatisfaction with available information indicate potentially serious problems with both doctor-patient communication and the overall promotion of vaccination as an important healthcare practice. Clearly, participant reports of clinical conflict and/or the nature of provided information cannot be taken at face value; however, they do point to potential areas of further study and possible intervention.

First of all, is the vaccine-related information currently available to both parents and

52 *Pädiatrie & Pädologie* 45(4):10-23, published 2010.

healthcare professionals in this context sufficient? According to Haditsch, every person receiving a vaccination has the moral and legal right to comprehensive information, including detailed information about the pathogen (how the disease is transmitted, what its symptoms are, and possible treatments) as well as the vaccine (including efficacy rates, possible side-effects, and counter-indications); this should be realistically achievable through a combination of written material and "vaccine-counseling" during physician's visits (Haditsch 2010:20). According to participant reports, some healthcare providers are failing to provide much if any of this information. There are many possible explanations for this phenomenon, from parental forgetfulness to practitioner irresponsibility; however, the distinct possibility exists that the information on offer is in fact insufficient and/or insufficiently accessible⁵³. This possibility warrants investigation, as does the possibility that time-constraints, remuneration, and other practical issues are impacting the ability of healthcare professionals to provide adequate counseling services.

In general, the demand for decision-making autonomy implies the need for a larger degree of transparency surrounding vaccination policy. Policy-influencing bodies such as the Austrian National Vaccine Council (*Nationale Impfgremium*, formerly the *Impfauusschuss*) need to be more explicit not only about *which* vaccines they recommend and *how* they should be administered, but also *on what basis* and *towards what ends* these recommendations are made. Any lack of transparency, both in regards to the recommendations themselves and to the process by which they come into being, may well encourage engaged parents to come to the conclusion that it is in fact economic interest and corruption, and not medically justifiable reasoning, that motivates policy choices. In today's largely individualized health climate, passive acceptance of medical recommendations is far from given; these recommendations must be *actively* promoted if they are to be accepted. It is true that a parent who is categorically against vaccination will be unlikely to be influenced by such arguments; however, the majority of participants in this study indicated a degree of openness to particular arguments in favor of vaccination, especially in cases where risk to the individual can be convincingly demonstrated. There is no reason to think that persuasive information, when provided in a respectful manner, will not have an effect on vaccine acceptance.

There is a tendency to frame vaccine-refusal as an entirely negative phenomenon,

53 For example, many of the topics cited by Haditsch (2010) are indeed addressed in the Austrian Vaccine Schedule (*Impfplan*). However, these schedules are highly detailed and comprehensive; for example, the most recent schedule (2013) consisted of 59 pages of dense text. This document contains valuable information, but its accessibility to parents is questionable. See <http://bmg.gv.at/cms/home/attachments/3/3/6/CH1100/CMS1327680589121/impfplan2013.pdf>, accessed 1.10.2013.

characterized by misinformation, misunderstanding, and above all mistrust. However, the level of consideration and concern that refusing parents have shown in these pages, alongside the willingness to actively engage in a complex and intimidating topic, can also be seen in a positive light. Front-line practitioners need to be aware not only of parental concerns, but also of the value placed by many parents on active decision-making autonomy, which must include critical engagement with expert-provided information. Without this understanding, conflict and mistrust will inevitably result, with very real implications for vaccine acceptance. Better understanding of the concerns and objections of uncertain and/or refusing parents, on the part of both experts and front-line practitioners responsible for vaccine counseling, has the potential not only to improve vaccination acceptance, but also to relieve significant anxiety and concern on the part of engaged parents.

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Curriculum Vitae

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Education

- October 2008 – December 2013 Masters Program in Cultural and Social Anthropology
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Internships, projects and further studies

- Oktober 2008 – September 2010 Founding member, vice president and co-coordinator of *Maia- Pregnancy
and Birth Support Services for Migrant Women and Women in Need* (Pilot
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- January – June 2006 Nursing Unit Internship, Postpartum Ward
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- September 2005 – June 2006 Further studies in the natural sciences (Biology and Microbiology, Organic
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Seattle Community Colleges, Washington, USA
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Employment

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Summer 2002 – Summer 2005 Extended travel in Europe, New Zealand, Australia and South/South-East Asia, including work in youth hostels, on farms and as a volunteer

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