gendering drugs

feminist studies of pharmaceuticals

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Sina Busse obtained her master's degree (MA) in European Studies on Society, Science and Technology at Maastricht University, the Netherlands, in 2014. Her interest lies in public health, and she is studying Health Economics at the University of Cologne, Germany, exploring links between science and technology studies and medicine, public health and health communication.

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Lisa Lindén is a lecturer in the Department of Sociology, Stockholm University, Sweden. Her primary research interests concern gender, sexuality and technology in medicine. Her work has been focused on human papillomavirus vaccination and the design of biomedical experiments. She is the author of *Communicating Care: The Contradictions of HPV Vaccination Campaigns* (2016, Arkiv förlag/Arkiv Academic Press) and has published in *Girlhood Studies*, *Catalyst: Feminism, Theory and Technoscience* and *Journal of Cultural Economy*.

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Tara Mehrabi has a PhD in Gender Studies from Linköping University, Sweden. Her PhD thesis, *Making Death Matter: A Feminist Technoscience Study of Alzheimer's Sciences in the Laboratory*, is a study of ethics and politics of knowledge production practices in the laboratory, within the context of Alzheimer's disease. Her research interests engage scientific practices around killability, human and fruit flies' relations, and biological waste within the theoretical frameworks of new materialisms, feminist technoscience studies, human and animal studies, and science and technology studies.

Celia Roberts is a professor of Gender and Science Studies in the Department of Sociology, Lancaster University, UK. She is the author of *Puberty in Crisis: The Sociology of Early Sexual Development* (2015, Cambridge University Press) and *Messengers of Sex: Hormones, Biomedicine and Feminism* (2007, Cambridge University Press), and the co-author, (with Sarah Franklin), of *Born and Made: An Ethnography of Preimplantation Genetic Diagnosis* (2006, Princeton University Press).

1

Introduction

Ericka Johnson

The title of this volume, *Gendering Drugs*, is a double entendre. It speaks to the idea that pharmaceuticals can be gendered—perceived as being masculine or feminine, for men or women—by the bodies and symptoms they are supposed to treat, by market forces and marketing campaigns, and by user demographics. Just think of the infamous little blue pill, Viagra, and the attempts to sell a pink version of the same blockbuster drug (Cacchioni 2015). The other meaning in the title suggests the ways that pharmaceuticals create gendered subjectivities for us, the users. Pharmaceuticals can articulate gendered values, norms, behaviors and expectations that we as users (or misusers, or resisters) must respond to in some way. Drugs can be gendered and they can engender us.

The chapters in this book result from a collaborative research project that examined the way pharmaceuticals create understandings of "healthy" subjectivities for us. We, the authors of the following chapters,

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looked at pharmaceuticals that are used on the outer edges of adulthood to discern the discourses in which those drugs were embedded and what the drugs expressed about understandings of the healthy, adult subject. With these questions in mind, we individually analyzed discourses about different drugs for young people on the cusp of adolescence (the HPV vaccine and the use of hormones to delay puberty) and about drugs for the aging adult body (pharmaceutical treatments for prostate problems and for Alzheimer's disease). We examined what was said and imagined about the medicated bodies about to become and leave the subject position of the healthy adult. We asked how drugs were thought to shape, facilitate or delay the assumption and loss of a healthy subjectivity in commercial, medical and user discourses. Then, through a series of workshops, we collectively discussed what our findings said together about pharmaceuticals, subjectivity, society and, as this book explores, gender.

As we studied the discourses around these pharmaceuticals, we learned a great deal about what being a healthy subject is thought to entail, at least in the imaginations of pharmaceutical marketing campaigns, health policymakers and medical practitioners (see Roberts 2015; Johnson et al. 2016; Lindén 2016). And throughout the project, we applied theoretical insights taken from feminist technoscience studies to our material, theories which have helped us articulate that, and how, those subjectivities are gendered, as well as raced, aged and localized within nation-state boundaries, even as they are implicated in global discourses of universal bodies and objective, evidence-based medicine. All of us working on this project have been trained in feminist technoscience studies, so it was expected that we would take a feminist approach. But, as we progressed and collaborated, we started to wonder about the specificities this background gave our work and our readers. What did it mean for our research that we saw gender when we looked at drugs, and what difference did it make that we identify as feminist academics?

Our use of the term "feminist" signals a desire to work with our research in a way that cares about social justice, equality and inclusion—not just for women but for all humans. When turning this concern specifically to a critique of medicine, we find that we are still enmeshed in the same conundrum that Ehrenreich and English articulated back in the early 1970s: we are critiquing and criticizing much of the thought and practice of patronizing, sexist, Western medicine, while at the same time demanding access to the promise of health it tempts us with (Ehrenreich and English 1973: 87). But in our studies, 40 years after the epistemological upheaval signified by *Our Bodies, Our Selves* (Boston Women's Health Book Collective 1973) and Ehrenreich and English's work, and guided by recent studies which look at the details of technoscience practice to explore the political fluidity and entanglements of health care (cf. Thompson 2005; Murphy 2012), we are using feminist critique to encompass concern for masculinities, non-binary sex/gender understandings and locally specific gendered subjectivities that intersect with sexuality, class, race and global inequalities.

A further strength of our feminist technoscience approach is that it extends our analytical concern to nonhumans. Mehrabi, for example, articulates in Chap. 2 a clear posthuman approach—and relates it to social justice while problematizing where and how boundaries are drawn around what is considered to be and valued as social. The rest of us also find traction with strands of new feminist materialisms, seeing the material world intra-acting in relationally constructed subjects. Rather than imagining subjectivity as something possessed by a human (or possibly an animal), we see it as emerging in entanglements of humans and nonhumans. In this, several of us are inspired by work from Barad (2007) and Suchman (2007), and from posthumanism (see Åsberg and Braidotti 2017). Not least, this approach has allowed us to include the physicality of pharmaceuticals in our theoretical lens, and it has helped us to question the onto-epistemological basis of our work and the discourses we have studied.

In addition to including the material world, our feminist approach to articulating subjectivities is concerned with the temporal and situated aspect of subjectivity, the permeability of the body and the distributedness of the "I" (see Mol 2008; Gentile 2016; Schnabel et al. 2016). Much of our work thinks through the subject in relation to sexualities and the body, sometimes informed by psychoanalysis and corporeal theory (Grosz 1994, 2012) and by Kristeva's work on abjection, the instability of the subject and the political traction found in ambiguity, especially as related to abjection and trans (see Phillips 2014). And for others of us, this feminist concern with social justice has forced closer attention to the structural elements of health care in neoliberal societies, asking what room is allowed or facilitated, encouraged or promoted for different subject positions and what role the nation-state has in this (see Gill and Scharff 2013).

1 Sex/Gender

A variety of terms for sex and gender are used in the following chapters. In English, "sex" had initially been applied to the biological sex of the body, often determined by the externally visible sex organs and almost always within a binary system. "Gender" was then applied to the cultural aspects of being a girl or boy, man or woman in social interactions. In Sweden, where much of the research on this book was done, the term *genus* was introduced in the 1980s as a counterpoint to *kön* (biological sex) (Hirdman 1988) and today "gender" is also being used (see Lykke 2010). In both linguistic contexts, though, feminist work on the sexed body has problematized the notion of binary sex, sex connected to anatomy, sex connected to chromosomes, the performativity of sex and sex as a useful category at all (Butler 1990; Fausto-Sterling 2000; Kraus 2000). Likewise, the distinction between nature and culture has been problematized since it was first made (Haraway 1991; Hird 2004; Barad 2007; Braidotti 2013). Where a material-discursive cut (Barad 2003) is made between what is the biological about a sexed body and what is the social of a gendered subject is also problematized. It is not necessarily apparent and perhaps sometimes even arbitrary, and even the dichotomy itself is often questioned. And, since several of the pharmaceuticals that have been studied here are in some way related to sexual practices, the term *sex* appears in many of these chapters referring to sexual practices and sexuality as well, adding to the confusion.

Because of these layers of nuance, each of the authors has been careful to define and explain their terminology. The reader can expect to find references to biological sex, sex differences, sex, gender, sex/gender and even trans, the latter being used specifically to resist the distinction between sex and gender. Sometimes these terms are analyzed for the work they do in established discourses, and sometimes the authors use them to further their own arguments in the chapters. And in several of the chapters, the authors focus on the discursive practices that are creating sex or gender and thereby use the verb form to highlight the doing or creation of sex and gender by, through or in collaboration with pharmaceuticals.

2 Methods and Material

We are all positioned differently within the academy. Some of us work in a sociology department, others in a science and technology studies environment and others in a department of gender studies. Additionally we are all members of interdisciplinary research groups and centers that span these divides. Yet our shared background in feminist technoscience studies produced an interest in the material-discursive body (Haraway 1997; Barad 2007) at the pharmaceutical nexus (Petryna et al. 2006), even as we approached that material-discursive body and the self with very different methods.

The chapters in this book examine discourses, envisioned as material-discursive entanglements or practices. These have been gathered through qualitative methods: exploring archive or textual materials, as well as interview and ethnographic data recording encounters with doctors, nurses, policymakers and also with pharmaceutical users and resisters. We have analyzed media material and medical textbooks, and also include commercial material and non-academic literatures. To do this, we have used variations of discourse analysis to trace the discursive contours of race, gender, sexuality, culture, religion, ethnicity and age in implicated subject positions and collectives; to draw out unarticulated but formative political concerns in a discourse; and to articulate assumptions, norms and values that make possible, underpin or enable perceptions, arguments and performances of health and disease (cf. Laclau and Mouffe 1985; Fairclough 1995; Lykke 2010).

3 Overview

We have organized this book into three parts, each with its own approach and empirical area. Part I examines pharmaceuticals in different phases of scientific and medical material-discursive practices. Here the reader will encounter a feminist critique of scientific practices early in the pharmaceutical production chain, a pharmaceutical treatment as it is embraced by the medical establishment and an examination of how users (intended and unintended) approach the ability of a pharmaceutical treatment to align their bodies with their experienced subjectivities.

In the first chapter of Part I, "Alzheimer's in the Making: A Feminist Laboratory Study of Alzheimer's Disease," by Tara Mehrabi, the reader will find an analysis of fly models as they are used in a laboratory experiment to develop a treatment for Alzheimer's disease. Employing participant observation, Mehrabi worked as a laboratory assistant whose job it was to breed and sex determine generations of virgin female flies. To this material she applies theoretical tools commonly found in feminist technoscience studies, namely, concepts of materialization, embodiment, subjecthood and care practices. She shows that the doing of sex—the sexing of the flies—becomes an intrinsic part of Alzheimer's disease materialization in the laboratory. Mehrabi's work speaks about how knowledge is produced in the material-discursive practices of science, science which is funded to produce knowledge that can lead to pharmaceutical treatments. She reflects on the long history of studies of knowledge production and pauses to consider Fleck's (and Bohr's) contention that observation changes the object of investigation. But then she expands on this using Barad's onto-epistemological approach, which opens up a posthuman space of performativity, accounting for nonhuman modes of world making, and nonhuman agency.

The next chapter in this part, "The Pharmaceuticalized Prostate," by Ericka Johnson, also draws on concepts of nonhuman agency. In it, Johnson examines the *collectifs* of intra-acting actants that construct a prostate treated by pharmaceuticals. This chapter relies primarily on an analysis of different diagnostic and treatment guidelines for lower urinary tract syndrome secondary to benign prostate hyperplasia and begins with questions about the political implications of how bodies, diseases and subjectivities are constructed, enacted and defined. These are questions commonly found in studies which have taken women's bodies and medical science practices as their empirical field (Laqueur 1990; Martin 1992; Oudshoorn 1994; Fausto-Sterling 2000; Das and Addlakha 2001). Applying these to male bodies, the prostate and pharmaceutical treatments of it, Johnson examines the use of alpha-blockers as an actant in the pharmaceuticalization of the prostate. She queries the pills to ask: what does it mean to look for "health" when "health" is defined as medicated urination with minimal or at least tolerable side effects? This concept of "health" requires a pill that is ingested daily for the rest of one's life. What sort of understandings of health and the healthy subject position are created by lifelong medication?

In the final chapter of this part, "New Puberty; New Trans: Children, Pharmaceuticals and Politics," Celia Roberts and Cron Cronshaw analyze discourses describing the use of gonadotropin-releasing hormone analogues in trans children. Like Mehrabi, Roberts and Cronshaw use the verb "sexing" to indicate the complex process of creating, defining and articulating sex. They argue that the prescription and consumption of these drugs are entangled in the production of new forms of subjectivity and life/experiences. Their analysis explores what questions are opened up around sex/gender, pharmaceuticalization and ethics by this intervention into children's bodies. Drawing on early feminist work by Ehrenreich and English (1973), this chapter remains within the tension between a critique of and resistance to sexist, classist and racist medical thought and practice, and the desire for treatment. As they write, this entails "recognizing that felt needs and bodily (in)capacities are produced—at least in part—by the same discourses and practices that promise to address or intervene in them" (p. 80, this volume).

Part II of this book looks at commercial images and discourses that advertise pharmaceutical treatments. While the construction of individual subjectivities and their intersectional elements are clear and interesting in this material, we have analyzed them elsewhere (Åsberg and Lum 2009; Lindén 2013; Johnson et al. 2016). What we write about here is the way commercial discourses also prescribe relational practices for those subjectivities. Not only are the individuals imagined as consuming the pharmaceuticals both constructed and colored with social characteristics, but the pharmaceuticals are also inserted into the social relations those individuals are imagined as having.

Chapter 5, "Prescribing Relational Subjectivities," by Ericka Johnson and Cecilia Åsberg, explores pharmaceutically mediated or prescribed relationships between heterosexual couples and across generations in their examination of three ads, one for a prostate treatment and two for a pharmaceutical that claims to delay cognitive degeneration. An important insight from this analysis is that the relationships prescribed by the pharmaceuticals also implicate additional people into the realm of pharmaceutical concern, both expanding the number of individuals who can be addressed by the drug and widening the areas of life which can (allegedly) be helped by taking it.

The expansion of the pharmaceutical subject constellation and the insertion of a drug into a relationship are also seen in Chap. 6, "You Will Protect Your Daughter, Right?" by Lisa Lindén. In it, she shows how the human papillomavirus (HPV) vaccine in Sweden is presented as a necessary component in appropriate and responsible mother–daughter relationships, articulating gendered parental care practices through the trope of parents-as-consumers and as managers of health risks. In this discourse, pharmaceuticals become essential, nonhuman participants in the parent–child relationship.

Continuing on with the HPV vaccine, Part III examines gendering in HPV campaigns in three additional nation-state contexts. Whereas Chap. 6 looked at subjectivities associated with HPV vaccination in Sweden, this part moves to Colombia, the UK and Austria, each of which presents HPV very differently to their populations and each of which regulates and distributes it through very different policy frameworks.

Chapter 7, "Evidence, Sex and State Paternalism: Intersecting Global Connections in the Introduction of HPV Vaccines in Colombia," by Oscar Javier Maldonado, starts out by detailing the way in which HPV was sexed and de-sexed through connections to representations of gender, sex, race, class, male sexuality, cancer and legitimate medical knowledge. Maldonado traces the way sex as a practice and a risk factor appears and disappears as the Colombian discourse moves from justifications of public-funded vaccinations to campaigns about public health. He then explores the conflict between expert, medical opinion and public understanding which appeared when the adverse effects of the HPV vaccination were claimed to be widespread by the local population in a Colombian town and exemplifies the analytical value of recognizing the relationship between disease and social difference.

This is followed by Chap. 8, "Young Women and the Pharmaceutical Burden of HPV Vaccinations," by Ali Hanbury, which explores claims regarding the adverse effects of the HPV vaccination in the UK. In in this context, girls' bodies are made responsible for the herd's immunity, which has implications for what acceptable feminine identities are available to them (i.e., vaccinated ones) and on how their injury claims are received and perceived. Her close work with injury claimants is contextualized against school vaccination practices. Hanbury suggests at the end of her chapter that the burden of responsibility placed on girls' bodies would be greatly reduced if boys too were vaccinated.

The final chapter of this part looks at a context in which this is the case. Chapter 9, "Two Shots for Children," by Lisa Lindén and Sina Busse, explores the HPV vaccination policy and associated official documentation in Austria, which has decided to vaccinate both boys and girls. This decision creates a context in which the often feminine-colored HPV vaccination (usually sold as a vaccine against cervical cancer) becomes a gender-neutral vaccine (against several other kinds of cancer, too, including penile cancer), for all children and for the nation as a whole.

In the book's concluding chapter, Chap. 10, "Sexing Drugs, Refracting Discourses," Ericka Johnson returns to the theoretical concerns shared and developed by the various authors to discuss their work within the context of subjectivity. She also discusses their empirical findings through the concept of refraction.

As we hope becomes clear to the reader, our starting point with this project has been to articulate voices and values in the discourses around pharmaceuticals and healthy subjectivities, grounded in feminist concerns about social justice. The results presented in this book are one of the ways we find to be political about pharmaceuticals and the body.

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Part I

Making Scientific and Medical Truths

2

Alzheimer's in the Making: A Feminist Laboratory Study of Alzheimer's Disease

Tara Mehrabi

This chapter draws on ethnographic observations made as I worked as a lab assistant, taking care of flies for an Alzheimer's disease (AD) study. It discusses the process of sexing flies and selecting virgins, which I did at different points, twice a day for the year of my fieldwork. Employing feminist science studies theories on onto-epistemological questions that my lab time triggered, I show how discourses of binary sex and of the genetic component of AD are refracted through the bodies of the flies as they become AD flies in the knowledge phenomena of the laboratory. I see AD as a science in the making, and I approach it with an interdisciplinary take. I read practices of AD biochemistry and molecular biology together with feminist technoscience studies, feminist materialisms and science and technology studies.

Scientists in this lab were trying to understand and unravel the mystery of AD's etiology on the molecular level through modeling AD-like biochemical processes in fruit flies, known as *Drosophila melanogaster*,

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and by means of genetic modifications. I worked with the research team as a technician as I bred transgenic Alzheimer's flies, videotaped them for AD measurements and imaged them so as to create an AD phenotype. During my time in the field, I also conducted interviews about my fieldwork with not only the scientists in the lab but also other scientists who were engaged with Alzheimer's research in other departments of the university.

AD is the most common type of dementia and a major matter of concern for national and global health (Moser 2008). Lock refers to it as the "epidemic of the twenty-first Century" (Lock 2013: 12) and a sociocultural, economic, political and medical concern, bringing together a variety of issues related to health care, insurance policies, drug industries and science laboratories. My work has explored AD in the lab.

AD has been a science problem for over a hundred years: a science problem to be analyzed, visualized and standardized in and across laboratories (Whitehouse et al. 2003; Lock 2013). Even though, over the past 100 years, science has been successful in underpinning the pathology of AD on the molecular level, the etiology of the disease is still a mystery (Lock 2013). The most common AD drugs, such as Aricept (donepezil), control the symptoms and increase the quality of life rather than cure AD. And, more recently, the location of AD pharmaceutical research has shifted from industry to small R&D and university laboratories, where the story of AD's neuropathology began in the early 1900s. As such, AD has changed from a promising, profitable and prospected market for a killer drug into a scientific curiosity in the laboratory.

1 Background

Within feminist studies and the social sciences, AD has been discussed in different ways, ranging from a cultural analysis and critical perspective on representations of the AD patients, to material-discursive and embodied realities of AD. AD has been a fascination of some feminist scholars.

Margaret Lock writes about AD and its uncertainties within scientific practices and clinical practices (Lock 2011, 2013). She argues that one of the main hopes within the natural sciences is that with the help of high-tech, novel scientific endeavors to detect AD at the molecular level, the disease can be prevented long before the symptoms appear. Today, by means of imaging technologies, one can measure the misfolding protein accumulations and AD-related plaques in the spinal fluid, just as one can also detect the AD-related gene ApoE4 by genetic screening (Lock 2013). Nonetheless, AD diagnosis always suffers from uncertainty because none of the molecular symptoms indicate that the person would actually develop AD, only that they are more at risk of getting the disease. In other words, as Lock writes, AD is a matter of "generation and transformation of expert knowledge and practices in connection with the phenomenon of AD, in an era of increasing uncertainties and recognition of apparently boundless complexity" (2013: 4). Lock's focus on the AD debates, publications, clinical procedures, conferences, media and so on leads her to see what happens to the healthy people, those who may never become ill even if they have the genes or the AD-related misfolding proteins, once these preventive measures and diagnostic technologies become part of routine clinical processes. She concludes that other forms of prevention such as lifestyle changes, reduced exposure to toxins, a decrease in poverty and/or increased community support might be a more successful way to handle the social dilemma known as AD rather than invasive, expensive, time-consuming "molecular micro-medical management," which often is available only in wealthier countries (2013: 4). In other words, she suggests that a more effective way of dealing with AD might be to shift the focus from the purely medical takes on brain and AD causation as a neuropathological and medical phenomenon to "the boundary-traversing mind, to persons, and to social and political milieu" (ibid.: 238). This is not to overlook the medical and scientific fight for a cure but to lead to a more inclusive approach toward AD than fetishizing it in the brain and as an exclusively scientific and medical problem.

Another approach, taken by Åsberg and Lum (2009, 2010), argues that AD discourses within the popular culture and pharmaceutical advertisements are deeply entangled with concepts such as dignity, loss of the self, cognition decline, self-care, successful aging and the ideal of the self-sufficient subject of modernism and neoliberalism (see also Wearing 2013). As such it is as if the subject is "fading away": becomes the other, the animal, the monstrous, the "Zombie" (Behuniak 2011) which triggers the sociocultural anxieties around AD. While the sociocultural anxieties and frustrations about AD are discussed in these works, they emphasize that such negativities are often due to the disruption of the modernist human subject, the myth of human exceptionalism and dis-configuration of the self's clean and close body. These scholars argue that it is not AD that is the problem but it is the modernist understanding of human subject, personhood and body/mind dichotomy that needs rethinking. For instance, Åsberg and Lum (2010) take the materiality of body and the relational realities of AD as a crucial node for unpacking, which would allow discussing AD beyond the limits of humanism. In other words, they write about the agency of the proteins that take over the body in the case of AD and disrupt the modernist imaginary of a clean, closed body, a subject in control of his body and the human as the center of AD reality. In another application of the posthumanist analytical lens, Kontos (2003) discusses AD through the paintings of the abstract expressionist Willem de Kooning, to argue that the subject interacts with the world not with the (conscious) memories but in remembering how to be in the world in a bodily sense. She argues that Kooning could paint even after developing AD, which problematized the western imaginary of brain as the locus of memory and personhood in favor of materiality of the body and embodied memory as an alternative mode of understanding personhood.

My analysis of AD as a science in the making is different from Lock's, Åsberg and Lum's, and Kontos's. To discuss AD in relation to debates, conferences and discourse of AD, or to say AD's "style of thought" on the one hand, and to speculate on the performative effects of such "presymptomatic" (Rose 2007) measures on humans is of course a crucial part of AD as a science in the making; but it is not the whole story and it is one of the other stories about AD as a science in the making that I discuss in this chapter.

In order to understand AD as a science in the making, I look into day-to-day practices of knowledge production in the laboratory, long before the scientific results officially become part of the scientific discourse as publications. As I will show, AD as a *science in the making becomes partially situated, ever-changing processes of knowledge production*. As a by-product of such understandings of AD, I go on to discuss that it is not only AD which is made and produced in the lab, but also that taken-for-granted realities such as sex differences are remade. Moreover, objects such as fruit flies are also produced and black-boxed as model organisms through such knowledge phenomena (Latour 1987). In everyday practices of doing AD sciences, fruit flies, Alzheimer's-related genes and sex become constitutive parts of one another in peculiar, nonseparable ways. Last but not least, to understand AD as a material-discursive "phenomenon" (Barad 2007) also allows me to take the materiality of the body and proteins seriously, offering alternative modes of understanding reality. AD as a phenomenon becomes a relational material-discursive becoming, and a material mode of being in the world that go beyond the human subject/consciousness.

In discussing AD in the lab, what I am interested in is the relation between biological sex and AD. Even though the scholars mentioned above highlight the importance of embodiment and as such the importance of the power differentials such as biological sex/gender in enacting realities of AD,[1] sex/gender is more of a central concern to studies that deal with the question of care and ethics. AD is often discussed in terms of its social impacts, practices of care and ethics, all of which are deeply situated within and impacted by gender norms. For instance, some scholars explore the female spouse, daughters and daughters-in-law as the main care provider for AD patients (Paun 2003; Persson and Zingmark 2006), while others focus on the gender-crossing practices of care in which male and female caregivers go beyond the boundaries of conventional gender roles to provide care for their loved ones (Calasanti and Bowen 2006).

Here, however, I explore biological sex and AD as material-discursive relationalities of a different kind. In this chapter, I wish to write about sex differences not in terms of norms and practices of care or representations of AD in popular culture but within Alzheimer's sciences in the laboratory. The relationship between sex and science has a rich history within feminist science studies. For instance, the question of "women in science," namely, female scientists' visibility and engagement with sciences, has been discussed at length (Ehrenreich and English 1978; Harding 2004). The reality of female scientists working with science in

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[1] For instance Åsberg and Lum (2009, 2010) show the gender-specific narratives and images of AD drug advertisements; see also Chap. 5, this volume.

laboratories, or as Wayne (2000) calls it "the feminist life" of a female scientist, has also been critically evaluated. Production of gendered subjectivity by scientific facts has also been explored (Roberts 2002). The importance of sex difference in constructing "nature" or "natural facts" as "natureculture" has also been greatly reflected upon (Haraway 1991; Hird 2004). The very relation between sex and gender in terms of scientific facts has also been discussed in debates about whether sex is natural and gender is a social construction or whether both sex and gender are social constructions and intertwined. The relation between the dichotomy of sex and gender, nature and culture has been explored so as to highlight the performative relation between sex/gender and scientific fact about sex differences (Fausto-Sterling 2000). Feminist technoscience has dislocated sex from its association with genitalia to go beyond the binary of male-female, culture/nature and gender/sex (ibid.). Sex has become fluid, while, at the same time, it is used to account for the materiality of the body. As such, biological sex as a material-discursive reality and against the modernist binary of male and female has been discussed in relation to animals; not only animals "big like us" but also in terms of "microontologies of sex" (Hird 2009: 91). However, in this chapter I am particularly in conversation with the work of Cynthia Kraus (2000) and her understanding of biological sex.

In her study of drosophila and sex determination factors, Kraus (2000) shows how sex differences pass the threshold of genitalia in which chromosomes are sexed while at the same time sex becomes an experimental tool rather than the source of culturally meaningful dualist sex differences as in male and female.

> Sexual difference does not precede the practice of sexing flies as some material substance inscribed in 'pre-scientific' flies, but is carried along through an *antecedent set of materializing epistemic practices*, those of earlier experiments in the history of Drosophila biology made "nature." (Kraus 2000: 163, emphasis in original)

Kraus highlights the performativity of sex in producing knowledge within the life sciences using flies. She argues that the very practices of sexing the flies in the lab, separating male from female, has become such an intrinsic part of experimenting with the flies that it has transformed sex into an experimental tool. Such standard practices, according to Kraus, are processes "that bring[s] sex into experimental existence and remake[s] it into a tool" (Kraus 2000: 164). Sex as such is a performative tool "of a singular system of practices" which enacts one sex in opposition to the other as a particular mode of experiment (Kraus 2000: 164), but not in the traditional, fixed understating of male and female according to physical features such as sex combs or genitalia. Rather, sex difference (even though still employing a binary) becomes meaningful depending on the experiment. Sex becomes "an object whose very definition is suspended, and in suspense, in the experimental process" (Kraus 2000: 164).

I use this contribution from Kraus, in which sex is an experimental process and a tool which becomes meaningful in relation to particular experiments, in my analysis of ethnographic material from the laboratory. I show that to understand sex and AD together as a relational becoming which is mutually constituting, one must leave the boundaries of a binary male–female dichotomy. Sex multiplies as it becomes a matter of AD-related genes and enzymes, as much as it becomes physiological bodily specificities. This is, however, a mutual process. AD also becomes multiplied in terms not only of AD-related genes but also of the flies' bodily specificities and sex difference. This I see as a mutually "intra-active" becoming, within Barad's theory of agential realism (Barad 2007).

According to Barad, objects (better termed phenomena) exist only in intra-actions. In her theory of agential realism, Barad distinguishes between inter-action and intra-action. She argues that interaction assumes preexisting subjects—things, objects—that come together and represent what is out there. Abandoning this modernist concept, Barad suggests the term *intra-action*, which is the condition of the possibility of objects, subjects and phenomena becoming together. Intra-action implies the ongoing processes of mattering on the one hand and "agential separability" on the other hand (2007: 140). In other words, the world is an ongoing process of mattering, within which a phenomenon comes into being as singular only when agential cuts are made; only when a phenomenon is enacted in relation to a particular apparatus, and its boundaries set and determined, which provisionally "cut" the phenomenon and separate it from other, multiple possibilities of materializations. Barad's agential realism takes the apparatuses of knowledge production seriously and views it as performative. For Barad, an apparatus is a material-discursive practice that enacts difference. Measurements are therefore material-discursive boundary-making practices that enact the phenomenon in its materiality and its meaning as multiple yet distinctive (Barad 2007: 146). Applied to my study, an agential realist approach assumes that AD is ontologically inseparable from what is producing it as such, namely, fruit flies and sex difference.

Moreover, agential realism provides an alternative to anthropocentric understandings of agency. It discusses a phenomenon like AD as not only a human reality but also an agentially enacted and relational reality that is a matter of nonhuman actors, such as flies. According to Barad, agency is

> a matter of intra-acting; it is an enactment, not something that someone or something has. Agency cannot be designated as an attribute of a 'subject' or an 'object' (since they do not preexist as such). Agency is not an attribute whatsoever—it is "doing"/"being" in its intra-activity. (Barad 2008: 144)

In other words, agency as *doing* and as enactments has nothing to with the intentionality of the rational subject. Neither does it reclaim or give back the object's agency. Agency does not empower the other. Agency as enactment and *doing* is "a matter of changes in the apparatuses of bodily production" that take place in intra-action (Barad 2008: 144). It is the possibility for change. It is the *capacity* for nonhuman resistance which has to be regulated constantly.

Law and Lien (2013) argue in similar vein, understanding agency as *capacity* for agency as a relational reality that is enacted differently in doings. In their ethnographic research about Salmon ontology, they argue how anesthetizing the salmon properly is a matter of *capacity* for agency. They write that the practice of anesthetizing the salmon "can be understood as a set of repetitious relations including people and physical materials that enact 'the salmon passive,' or perhaps 'the salmon not passive enough'" (Law and Lien 2013: 368). The "offending fish" ends up in the waste bucket while the passive salmon moves on (Law and Lien 2013: 376).

The agency I am concerned with, as the matter of *capacity* for agency, is indeed the moment in which the capacity for the agency of the nonhuman has to be regulated in practices of doing AD. It is about the offensive moments. It is the story of things that go wrong, flies that do not hatch in particular temperature, flies that resist genetic alternation or flies that simply fly away.

2 AD in the Lab: A Precursor to AD Pharmaceuticals

Dementia has long been associated with aging or senility. However, through the discovery of tau tangles and A-beta amyloid plaques, and with the new technological possibilities, AD as a form of dementia was developed and transformed from a mental disease into a neurophysiological disease, and the potential target of pharmaceutical treatments. As an effect of this ontological shift, practices of doing (diagnosing and treating) AD also shifted, as did the authority of by whom the diagnosis has to be made. AD is now a technoscientific artifact, science in the making in the laboratory on the molecular level. As a matter of changes within the style of thought about mental illnesses, the change and establishment of neuropathology as a field of knowledge, and novel technological assays, AD has become a matter of proteins, enzymes, antibodies and genetics as much as its clinical symptoms. AD's neuropathology has standardized on the molecular level gradually (over decades) to the point that tau tangles and A-beta plaques have become the most dominant hypotheses within dementia science, as my informant in the lab told me. AD has become a neuropathological condition, a scientific reality, a technoscientific artifact, visualized in standard ways, some of which are also the means of diagnosing the disease. However, this process of knowledge production about AD is still an ongoing affair. For example, creating novel forms of staining techniques is an ongoing part of Alzheimer's science. Scientists aim to develop smarter molecular agents that not only can give clearer images of the misfolding proteins but also can dissolve those bundles in early stages, before the disease breaks out.

In the laboratory of my fieldwork, scientists were working not only to develop molecular agents that bind to one of the proteins associated with AD, namely, the amyloid beta (since many such radioligands already exist), but also to develop an agent that can give them a clear and sharp reading of the proteins. Moreover, as the by-product of their experiments, they also hoped to find therapeutic molecular agents that could bind to these radioligands and dissolve the amyloid beta in the brain. Their experiments were often modeled in flies or mice because according to my informant they have not yet found a “smart agent” that can pass through the human brain’s blood barrier. In scientific terms, they were trying to understand the complex toxic mechanisms of misfolding proteins, proteinaceous aggregations and neural degeneration, using a variety of modern technologies such as molecular imaging in order to be able to detect AD in its early stages. They hoped not merely to provide molecular tools for early diagnosis, but also to be able to prevent the progress of this multifaceted disease by inhibiting toxic protein formation. Though, as much as AD was a dominant theme in the lab it was not exactly AD sciences that scientists were doing in the lab.

In what I saw during my fieldwork, AD in the lab was enacted both as AD and as not AD. In this lab, scientists were working on AD since they were using transgenic flies which were genetically manipulated with the genes and enzymes related to AD. They were experimenting on the AD-related misfolding proteins and processes of A-beta aggregation. Their project was funded as an AD project, and they would be publishing within the AD discourse. Yet, it was not AD as such (as in humans or in the clinic) that they were doing.

Me (during an early interview with one of the scientists in the lab):	Can you explain about your project and its relation to Alzheimer’s disease?
Lina:	It is not really Alzheimer’s that we do here.
Me:	But it is related to AD? Isn’t it?
Lina:	Yes. On the molecular level it is. But it is not comparable as such with the clinical diagnoses in humans. Also what happens in the human body is not comparable with what happens in the flies.

Lina explained to me that the funding for the project was to support Alzheimer’s research; to promote research on finding a cure for the disease. But, in reality, they (Lina's research team) were far from finding the cure. They were (like many other AD labs) still struggling to understand the causation of A-beta misfolding so that they could find the proper target for the future cure (yet to be developed). Moreover, the scientists in the lab were not particularly looking for an AD treatment but for A-beta misfolding diseases including AD. Nevertheless, their research outcomes were most likely to be published within the contemporary discussion on AD in biomedical, biotechnology and/or neurology journals. The chosen AD transgenic animal model for their experiment was also referred to (in the lab) as Alzheimer's fly or the AD fly.

While in the clinic AD is diagnosed via memory and cognition tests, AD in the lab is about misfolding proteins of A-beta and enzymes. Similar to the clinical diagnoses, laboratory diagnosis of AD is also about "the probable Alzheimer's disease" (Lock 2011). In other words, the misfolding proteins of A-beta of tau tangles are not only an indication of AD. On the molecular level, many protein diseases share partial features such as AD, Parkinson's disease and Lewy bodies. They share similar morphologies and they behave (partially) alike in their neuropathological effects. Thus, AD in the lab becomes a matter of doing, manipulating and simulating what is *known* as AD (always partial) and what is knowable as AD (always partial) on the molecular level in the transgenic flies. AD in these molecular practices *is* bits and pieces of what is known to be AD in humans, which is constantly being assembled and de-/re-/assembled in different combinations in the practices of *knowing* AD in the flies. *Knowing* AD is to know microbiology and the chemical functioning of the misfolding proteins, their mechanisms and behaviors in animal models, which is not comparable with what happens in human bodies, yet is made partially comparable as the means of knowing AD. The practices are making what AD is.

3 Sexing the Flies, Making Alzheimer's

In the following, I explore the material-discursive realities of AD in the lab as a matter of human and nonhuman relations. I wish to argue that sex and AD are constitutive parts of one another within the context of

AD sciences. It is in this agential relational becoming of AD that the agency of the nonhuman becomes performative for what AD becomes. I ask: What if sex is even more fluid than the substance of sexual difference? I conclude that if realities are enacted in relational practices, if components within phenomena—namely, object, subject and the apparatus—are constitutive of the phenomena but also constitutive of one another in the agential realist account, then sex, flies and AD are crucial parts of one another as they make each other.

As a technician in the lab, I worked with handling and breeding transgenic AD flies. As I worked, I realized that AD is not only a matter of genetic combinations of the human AD-related proteins, but also of regulatory balancers and markers. These balancers and markers were tools to regulate the agency of the flies, namely, their corporeal capacity of resistance toward AD-related genetic modifications. AD was also to negotiate and control the agency of the flies, namely, their capacity of doing, of flying away, through sedation. AD was also about materiality of the flies' bodies and sex difference which I discuss in the following.

Breeding the flies was a crucial part of doing AD in the lab. In breeding the flies I was not only modifying AD flies, but these flies would be my point of reference in my attempt to define what AD *is*. I had to measure these flies after I made them. If the experiment results conformed to the dominant AD discourse, my flies would have become an AD phenotype. In other words, I was modifying AD flies in relation to already established, dominant discourses and routine practices of AD, to make a new AD phenotype which would in turn describe what AD is. In breeding the flies I was performing AD, together with the flies.

I started the experiment with six distinctive sequences of AD flies. These six kinds of AD flies had to be bred into certain genetic combinations through the act of "crossing" (breeding a female of a certain genetic combination with a male of a certain genetic combination to produce offspring with characteristics from both) in order to reproduce a stable genetic assemblage for AD experiments. I will not go into the details of all the possibilities emerging out of the crossing matrix. Instead, I will focus on one particular sequence so as to illustrate the practices of AD in the lab. I will start by introducing two kinds of flies which were involved in the crossing experiment and breeding: 33797 APP flies (AD fly inhabiting the APP protein, a protein from which A-beta misfolding aggregates and BACE1, which is an enzyme that cleaves APP on the wrong amino acid) and DB:DB virgins wild fly. (DB flies are wild flies with white eyes that carry the marker and balancer genes. Even though they were genetically modified with markers and balancers, they were called wild flies because they did not have AD-related genes.) The markers (short hair on the back of the fly or irregular facade in the eye, or both) and balancers (more than two hairs on the shoulders or curly wings, or both) are genes that express significant morphological changes in the fly body which are then used in the crossings to track down the chromosome on which APP and BACE1 genes have been stabilized. This is to confirm that the collected flies have the genes required for the planned experiment. This was also about the agency of the flies.

I needed female virgin DB flies only. I did not collect any males of this kind. Markers are not an appropriate tool for tracking female bodies since a female body recombines genes. Markers do not perform the required stability of the balancers in a female body. Therefore, I had to collect females with balancers. In other words, female flies are enacted as active agents in the act of modification with balancers within the course of experiments. The corporeal *capacity* of the female flies to recombine, to resist the genetic matrix, enacts them as active agents and subjected to a stricter regulation within the AD practices and fly collection in the lab. AD flies in this stage were enacted in relation to their capacity for resistance and were regulated with the balancers. As such, all the other females were excluded. When speaking of exclusion here, I claim that exclusion is a necessary part of the AD becoming and as such the exclusion is not about *excluding form* but it is what Barad calls "constitutive exclusion" (2007: 205). The excluded flies are always already entangled with the non-AD flies because the excluded flies are the condition of possibility of the AD flies. In other words, in each crossing and in order to breed AD flies, many flies are born, some of which inhabit the "correct" AD-related genes and others are born with the "wrong," non-AD-related genes.

Moreover, AD flies were enacted not only in relation to their capacity for resistance but also in the matter of sex differences. As Kraus argues, collecting flies is deeply grounded in the male–female binary. This means that the decision of male-ness and female-ness emerges out of the dichotomous logic and an act of comparison and contrast. As Kraus writes, they would be *either-or* to *one another* and based on an exclusionary logic. The females are bigger while males are smaller in size. The males have a round dark bottom, while females have a pointy, light, striped bottom. The males could be detected by the presence of sex combs (the dark spots on the two front legs), which the females do not have. One becomes female only in the absence of what is accounted to be the male and the other way around. Moreover, these flies are sexed under the microscope according to not only their genitals but also their size, front legs and the color of their bottom. Practices of *sexing* the fly and *knowing* AD are entangled, which simultaneously produce AD flies as well as sexed flies. In both cases, the flies are produced as AD and sexed by being viewed through the sex binary.

3.1 Virgin Flies

The DB stock is a live, ongoing stock which we always maintained in order to breed DB virgins. Collecting virgins is a ritual which could go on for days before we collected the required number for the experiment (it often took between 7 and 10 days). I had to collect virgins twice a day, for a week. The virginity of the flies in the lab has a practical importance for the scientist. Collecting virgins ensures that the DB females are not impregnated with the “wrong” male flies. It ensures that the offspring have the genetic matrix needed for the experiments.

Twice a day, I had to sedate the flies and collect virgins. Then I had to separate the females, by looking for their balancers—counting the hairs on their shoulders, determining if their wings were curly. Then I had to kill the rest and make sure there were no flies left in the vials, just larva and pupa. To collect virgins, I started by emptying the DB tubes in the morning. Once I emptied the tubes, I had to leave the fly trays at room temperature for eight hours. It is believed that female flies do not mate in the first eight hours of their lives, which can ensure they are not impregnated. However, from the second day onward, my morning ritual was equal to the evening visits, with one difference: temperature. During the day and after my morning collection, I had to leave the flies in room temperature (about 21 degrees Celsius) until my evening visit. After the evening collection, I had to keep the flies at 18 degrees Celsius until the next morning. The lower temperature slows down the hatching from 8 hours to approximately 12 hours, which is convenient since the next visit to the lab would be in the morning. Temperature plays a crucial role in the fly experiments, and manipulates the fly life cycle, their hatching and the activation of temperature sensitive genes used for experimental reasons. So temperature became an important aspect of the phenomenon of AD flies.

In collecting DB virgins, enactment of the AD flies had reached far beyond the human and animal boundaries of the humanized APP transgenic manipulation and binary sex. Flies were a phenomenon of the life pace and cycle, temperature, spatiality of the incubator, the shelves on the wall and assumptions about fly reproduction habits and sexual behavior in practices of doing AD in the lab. In other words, sexing and collecting DB virgin flies for AD experiments exceeded the material boundaries of the flies' bodies while simultaneously locating their bodies in producing knowledge about AD. Only females with the balancers had to be collected for AD experiments (all the other females that did not express balancers became waste, as well as all the males). DB virgin flies and sex differences were becoming together, in the course of breeding AD flies. As such, assemblages of the genitalia and balancers mattered. AD was enacted as femaleness in terms of not only sex differences but also appropriation of the recombination phenomenon, as the control of the flies' corporeal agency and capacity for resistance in reproducing the desired genetic matrix. In other words, the very practice of sexing (sex as doing) the flies becomes an intrinsic part of AD materialization in the lab. If AD is a matter of situated doings and enactments in the lab, AD is then the mutual becoming of the AD flies, balancers and markers, and sex differences in moments of sedation and fly collection (when the nonhuman agency strikes the most), under the microscope.

It was not only the DB flies that I had to regulate and separate based on their genes and sex difference but also the genetically modified flies with AD-related genes. I had six different categories of such flies; each embodied bits and pieces of genes that would express AD-related proteins and enzymes in the flies (but not as in a human's body). Sometimes I also needed to collect male AD flies. Similar to collecting females, not all the males were enacted as males within the experiments because not all the male offspring born through crossbreeding the flies would be born with AD-related genes. Yet again, while some of the males were born with the red eyes of AD transgenic males, others were born with white eyes, indicating the absence of AD genes in their bodies. Only male flies with red eyes were collected as male AD flies in the experiment. It was as if maleness and AD were materialized in the flies as an assemblage of the red eye APP, curly wings, hair on the shoulders and irregular facade. As with the female virgins, AD and maleness were becoming, together, in the act of collecting the AD offspring.

4 A Feminist Take on AD as a Science in the Making

Within the course of the experiment and while collecting AD flies, AD became a constant multiple task in relation to sexing practices, making assumptions about fly sex behavior and life cycles, detecting AD-related genes and balancers, and practices of selecting and collecting the AD offspring. AD was constantly enacted as the source or cause of what was observable in the flies, as regulating their capacity for resisting the desired modifications. AD, as such, was multiple enactment of AD in practices of breeding the AD flies. It became a matter of intra-active agency and interrelationalities. In other words, practices of sexing and kinding became intrinsic to AD materialization and conceptualization in the lab. The feminist onto-epistemological approach of agential realism has helped me show this.

Practices of knowing and being are not isolated, but rather, they are mutually implicated. We do not obtain knowledge by standing outside of the world; we know because "we" are *of* the world. We are part of the world in its differential becoming. The separation of epistemology from ontology is a reverberation of a metaphysics that assumes an inherent difference between human and nonhuman, subject and object, mind and body, matter and discourse. *Onto-epistem-ology*—the study of knowing in being—is probably a better way to come to terms with how specific intra-actions matter (Barad 2008: 147).

To understand AD as a science in the making touches upon AD's historicity and its entanglement with dominant "style of thoughts" within neuropathology. As Fleck argues, "To observe, to cognize (*erkennen*) is always to test and thus literally to change the object of investigation" (Fleck 1929 [1986]: 53). In other words, to create knowledge about AD is an active process through which scientists do not simply observe but also make the object of observation, namely, AD. Therefore, to understand AD as a science in the making is to account for relations through which AD becomes what it is. As Fleck writes:

> *For cognition is neither passive contemplation nor acquisition of the only possible insight into something given. It is an active, live interrelationship, a reshaping and being reshaped, in short, an act of creation*. Neither the "subject" nor the "object" receives a reality of their own; all existence is based upon interaction and is relative. (Fleck 1929 [1986]: 49, emphasis in original)

What does it mean when I claim that AD is a matter of knowledge production practices? It means that I am concerned with modes of knowing that are involved in AD knowledge production practices in the biochemistry lab of my fieldwork. It means that I am interested in understanding how such practices perform AD as the lab's "made things" of science (Pickering 1995: 3). Indeed, to think with Fleck (1929 [1986]), I have investigated how practices of knowledge production about AD are creating the very object of inquiry relying on the dominant "style of thoughts" within molecular biology.

The knowing I am concerned with is not the knowing from nowhere. It is not objective and fixed. It is not produced in a vacuum and it does not to play the "God trick" (Haraway 1991). It is not the knowledge in the eye of the beholder, not something one has. It is "knowing in being" as Barad argues (2007). To know means to take seriously multiplicity, fluxes, mixtures of reality and relationalities, skills, technologies, animals, contingent scientific cultures and situated practices. Inspired by feminist technoscience scholars such as Kraus (2000), Haraway (1991, 1997) and

Barad (2007, 2008), I engage with the materiality of knowing as relational practice, multiple yet situated. And to use Fleck, cognition in this sense becomes situated practices of knowing, of becoming knowable and making things known in relations. AD then becomes always in the making: always in the *(processes of) knowing*.

Knowing is not the attribution of a cognitive mind on which it relies for existence. Knowing is located in relations or, as Barad (2007: 185) states, knowing is an "agential realist" affair that accounts for more than human agency. If "relations exceed relata," as she writes, then agency is located and distributed in the material semiotic moments of phenomena in which more than human rationality, perception, cognition and action matter and come to matter.

It is in this posthuman space of performativity that Barad and Fleck differ from one another. In other words, knowing as such goes beyond Fleck's anthropocentric, cognition-oriented, reality to account for the nonhuman modes of world making. *Knowing* offers accountability for nonhuman agency. It takes the world as a "witty agent" (Haraway 1991), "a generative flux" (Law 2004) that produces material semiotic realities. Being in, and knowing such a generative world, then means to appreciate uncertainties, constant negotiations and displacements that could only be stabilized momentarily via "agential cuts" (Barad 2007).

> In my agential realist elaboration, phenomena do not merely mark the epistemological inseparability of observer and observed, or the results of measurements; rather, phenomena are the ontological inseparability/entanglement of intra-acting "agencies." That is, phenomena are ontologically primitive relations—relations without preexisting relata. (Barad 2007: 139)

Drawing on Barad's agential realism has helped me to understand AD as a phenomenon. AD is not only the mingling of distinctive, autonomous humans and nonhuman actors (as in actor–network theory). Rather, AD as a phenomenon, as an enacted onto-epistemological becoming, is the condition of possibility for materializations of humans, nonhumans, sex difference and AD itself. AD's ontology is always already entangled with what make AD knowable. It is always entangled with apparatuses of bodily production with which AD becomes what it is. It is the onto-epistemology of AD that is at stake. I understand AD as a matter of agential realism that comes to matter in constant, shape-shifting intra-actions. As such, AD is not only material-discursive but also the subject matter of multiple modes of knowledge production. Alzheimer's becomes a mixed, performative, interrelated, mutually constructed, natural, scientific, cultural, social and material phenomenon.

Within the everyday practices of AD in the lab, what is at stake is not particularly what AD is, but which bodies are becoming knowable and known within the practices of knowing AD. Sciences that are producing knowledge about bodies are producing material-discursive bodies and simultaneously the world that those bodies are both of and inhabit. For instance, how transgenic Alzheimer's fruit flies are becoming a human companion species in the lab is at stake; how they are becoming the living test tubes that materialize AD and shape knowledge about AD is at stake. In other words, AD in the lab connects us with our nonhuman, biochemical natures: flies, proteins, enzymes. While at the same time flies' bodily specificities and boundaries, sex differences, as well as their pathological similarities with humans, not only give shape to our understanding about the human APP function, articulation and toxicity, but also formulate alternative future treatments for their human kin.

5 Conclusion

In this chapter, I looked into the practices of doing AD in the lab so as to claim that AD is multiple, situated enactments and practices of knowing AD in the lab: that it is a science in the making. I drew on the material I collected through my participant observation in a biochemistry lab in Sweden and interviews to argue that AD becomes what it is in a web of entanglements in which sex differences, genes and proteins, temperature, technologies and molecular binding are the name of the game. As such, human and nonhuman agency and entanglements are at the heart of this chapter. In other words, AD's multiple enactment is a matter of agency and posthuman performativity (Barad 2008).

Drawing from the long tradition of such work in feminist science studies, I argue that in order to understand AD as a science in the making, one needs to look into processes of knowledge production, scientific styles of thought, and the human and nonhuman relations of technologies and animal models with which AD becomes what it is in partial, situated ways. Though it is not only the discourse that I focused on, neither was it the human subject at the center of my study. I have written about situated relationalities as the condition of possibility for materialization of and meaning making about AD in partial ways. In other words, the multiplicity of AD is not necessarily about uncertainty. It is the possibility for AD to be materialized in meaningful ways as a matter of, assumingly, insignificant details within everyday practices like sexing the fruit flies in the lab. I analyzed practices of knowledge production about AD in one laboratory, in which AD is materialized and becomes meaningful through unprecedented relations that are often thought irrelevant when one is discussing scientific facts, namely, sex difference and fruit flies.

The practices I did in the lab produced AD flies through the intra-action of fly bodies, material practice in the lab, environmental factors like temperature, waste and the discourses of binary biological sex and genetic markers for AD. Analytically refracting the discourses of binary biological sex and AD genes through the flies produced a spectrum of fly bodies associated with male and female as known through physical characteristics (hair, shape, eye color, etc.). It also shows how those bodies reinforce the association of AD with genetic markers. It showed how sex and sexing processes are important for pharmaceutical development even before laboratory science has started working on a pharmaceutical cure or treatment.

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3

The Pharmaceuticalized Prostate

Ericka Johnson

This chapter discusses the use of alpha-blockers to treat lower urinary tract symptoms secondary to benign prostate hyperplasia (LUTS/BPH) as an example of how pharmaceuticals are involved in producing anatomical objects that can be associated with symptoms and diseases. It uses clinical guidelines for the diagnosis and treatment of LUTS/BPH and an analytical framework taken from feminist technoscience studies and science and technology studies, drawing on the tradition of thinking about how the gendered body is produced in and by medical technologies. With the concepts actant and intra-action, it articulates the material-discursive constellations that enact the prostate as a target for alpha-blocker therapies by thinking through the intra-actions of patients, bodies and pharmaceuticals. I will first give a brief history of prostate treatments and then read the use of alpha-blockers as described by the guidelines as an example of a pharmaceuticalized prostate.

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The materials I have used for this analysis are taken from three sets of different clinical practice guidelines: *American Urological Association Guideline: Management of Benign Prostate Hyperplasia* (BPH), published by the American Urological Association (AUA) in 2010; *Guidelines on Benign Prostate Hyperplasia*, published by the European Association of Urology (EAU) in 2006; and *Godartad prostataförstoring med avflödeshinder (Benign Prostate Hyperplasia with flow restrictions)*[1] by the Swedish Council on Health Technology Assessment (SBU) from 2011. The documents are meant to be guidelines for doctors who are confronted with patients presenting with LUTS/BPH. They are overviews and meta-analyses of current medical literature, and all three claim to have analyzed the scientific qualities of the various studies reviewed, choosing what they deem to be the most scientifically sound work, often assumed to be a randomized controlled trial (RCT) upon which to base their diagnostic and treatment suggestions. This sort of selection criterion is often called a gold standard and is what evidence-based medical (EBM) relies upon to create standardized medical and clinical practice recommendations. There are some differences between the three texts analyzed in this chapter, primarily in their opinions of alternative, herbal treatments, but their similarities are very striking.

1 Prostate Problems, Briefly

The guidelines analyzed here are not for the diagnosis and treatment of prostate cancer, but for LUTS/BPH. LUTS/BPH is a condition in which the prostate becomes enlarged but without being cancerous. The prostate grows and develops through puberty, and after first stabilizing in adulthood, it can start to grow again in older men, gradually increasing in size with age. This does not necessarily cause problems. But current medical knowledge suggests that when the prostate gets larger, it may also start to block the urethra, the tube that lets the urine pass from the bladder and which the prostate surrounds, like a straw stuck through a ball. It is when the prostate first begins to block the flow of urine through the urethra

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[1] All translations are the author's.

that the enlargement of the prostate becomes a problem. For some men, this occurs at around 50, for others not until they are 70 or more. This is a normal development, but this normal growth can cause problems with urination. By the age of 70, 75 percent of men will have BPH symptoms, that is, problems urinating (Parsons 2007: 395). Interestingly, in this case, the prostate becomes pathological when it is behaving normally. This is the theory on which the diagnostic and treatment practices explored in this chapter are based, but it is recognized as tenuous, even by the authors of the clinical guidelines analyzed here.

These days there are many different options to be found on the internet for men who want to avoid drugs and surgery. Some of these are as "simple" as relaxation techniques and massage (Wise and Anderson 2005), lifestyle changes related to diet or liquid intake and/or yoga and meditation (Parks 2010). There are also "natural" products for sale that target men who have or are worried about developing problems with their prostate, like medicines based on palmetto, pumpkin and stinging nettle, which are claimed to offer relief for urination difficulties. However, the first line of treatment for LUTS/BPH in standard, Western medicine (and in the guidelines analyzed here) is currently pharmaceutical, followed by progression to surgery if the pharmaceutical treatment is unsuccessful. The use of pharmaceuticals is a relatively recent change (it has partially replaced the traditionally more common surgery) and can be traced to the introduction of alpha-blockers in the 1970s (Heyns and de Klerk 1989: 226) and their eventual position as a standard treatment starting in the 1990s (Johnson 2016).

Urologists claim that urination problems have been an issue for older men for thousands of years, referring to images drawn on Egyptian papyrus from the fifteenth century BC and to writings by Hippocrates around the fourth century BC (Shackley 1999: 776). Medically, however, the prostate as a separate organ was not represented in European medical diagrams until 1538, and not named until 1611 (Marx and Karenberg 2009), and successful methods of surgically addressing the prostate for urination difficulties did not really evolve until just over a hundred years ago (Shackley 1999: 776).

At that time, a hundred years ago, patients were often encouraged to avoid certain activities to prevent their urination problems from getting worse or recurring, and to treat themselves at home. These home remedies included rinsing out the bladder with various solutions and the use of suppositories. Doctors would also recommend hot baths, sitz baths, bed rest, prostate massage (Marting Jr. 1903: 52, 56, 75; Kretschmer 1936: 11), and avoidance of prolonged horseback riding, sexual excitement and exposure to cold and damp environments (Marting Jr. 1903: 75, 144). Perhaps unsurprisingly, the newest technological advance at the end of the nineteenth century, electricity, also made an appearance in treating prostate and bladder issues.

At about the same time, it was generally thought that castration (by surgically removing one or both of the testicles) and vasectomy could be two treatments for the enlarged prostate that may have beneficial effects (Heyns and de Klerk 1989: 204; Shackley 1999: 777). This theory was in part developed because the then-current surgical methods (primarily suprapubic prostatectomy) had a very high mortality rate, so other treatment methods were welcomed by patients and doctors alike. Ideas about using castration and vasectomy can also be traced to the fact that doctors had noticed that eunuchs and those with non-developed testicles never presented with "hypertrophy" of the prostate (Chiechanswaki 1903: 91), thus indicating that the testes were somehow involved in the development of prostate growth. While clinical practice did not really support the use of castration for treatment—many doctors reported that it was not successful and that patients were not pleased with the results (Marting Jr. 1903)—the possibility that it could work eventually led to theories about the role of hormones in prostate enlargement. However, it was not until well into the twentieth century that hormone therapies were widely developed and used for prostate issues (O'Shea 2012: 17; see also Oudshoorn 1994, 2003 and Sengoopta 2006 for general histories of hormone treatments and their relationship to masculinity).

Because the concept of hormones was not yet in use at the time of the majority of castration attempts (in the late 1800s), the vague idea that the testes may be implicated in prostate hypertrophy relied on the understanding of testicles and the fluid they produced which was framed in terms of chemistry, not hormones. There were other chemical preparations that doctors prescribed for their patients, as well. These included opium, silver nitrate and belladonna suppositories, potassium iodine, potassium bromide, and ergot (a type of fungus that grows on rye) and large quantities of distilled water (Marting Jr. 1903: 52; O'Shea 2012: 14). Many of these treatments were directed at the symptoms with which the man presented with, primarily urination problems, and some of the elixirs were even used to irrigate the bladder; but others, like ergot, were actually thought to shrink the prostate gland (O'Shea 2012: 14), which can be seen as a precursor to the results of alpha-blocker use today.

After the turn of the last century, the medical community discovered hormones. This new paradigm had huge implications for the treatment of male virility and health issues related to aging masculinity, including prostate problems. In the 1930s and 1940s, androgens, especially testosterone, were used to treat patients with "prostatism," though without much success. The next step in this treatment trajectory was to try to use estrogen, and combinations of estrogen and testosterone. This did not really work to reduce the prostate, though it did seem to give some relief of symptom and urine flow (Heyns and de Klerk 1989: 221). In the 1970s and 1980s a series of trials were done on antiandrogens (which block androgen receptors in the body) and progestins (a synthetic hormone). Some of these showed symptom improvement and others did not, and many of the trials had quite a few side effects, like vertigo, shivering, tiredness, loss of libido and impotence (Heyns and de Klerk 1989: 221–223). Cholesterol-lowering drugs were also tested, but with no significant benefit (Heyns and de Klerk 1989: 23–24).

At the same time, in the 1970s and 1980s, doctors began to try alpha-blockers to treat the enlarged prostate, with more success. They seemed to be better than placebos at treating peak and average flow rates, the amounts of residual urine and even the prostatic urethral pressure (Heyns and de Klerk 1989: 226). The main goal of using alpha-blockers is to reduce the symptoms and, likewise, the bother of LUTS/BPH (SBU 2011: 317). Alpha-blockers work on the smooth muscle tissue of the prostate. One theory about the cause of some LUTS/BPH is that, as the prostate increases in size, the increase in prostatic smooth muscle tissue interferes with urethral constriction and impairs the flow of urine (AUA 2010: 13). Reducing this process and changing the behavior of the smooth muscle cells by ingesting alpha-blockers can then help to relieve the blockage and enable better urination.

However, alpha-blockers, which are taken orally, not only work on the muscle cells of the prostate, but also can affect smooth muscle cells all over the body, which means that some patients will experience side effects like headaches, dizziness, hypertension, retrograde ejaculation and, sometimes, erectile dysfunction. Newer versions of alpha-blockers, which are better at targeting the prostate, are being developed and marketed, but for the most part, treatment with alpha-blockers is related to various side effects. Nonetheless, the use of alpha-blockers has steadily increased over the last 20 years, partly because patients (and their doctors) see them as a way of avoiding surgery and partly because of increased marketing from pharmaceutical companies (EUA 2006: 35; Johnson 2016).

If alpha-blockers are going to work for a man, he should notice a difference relatively quickly, sometimes within 48 hours, and no longer than a month after beginning treatment (EUA 2006: 36). Different ways of measuring the results of treatment are commonly used to determine if alpha-blockers are effective, including iterations of the symptom scale questionnaire and pressure, flow and volume measures, and by measuring the volume of the prostate, to see if it has shrunk at all. These methods are the same as those that are first employed by a man's doctor to determine if the patient has LUTS/BPH, and the results of those initial tests are used as a baseline to determine if treatment is having an effect. An additional way of evaluating treatment success is if the patient decides to continue or discontinue treatment.

If alpha-blockers work, the patient can continue taking them for the rest of his life. According to the AUA, alpha-blockers "produce [such a] significant symptom improvement compared to placebo that the average patient will appreciate [it] as a moderate improvement from baseline" (AUA 2010: 28). But what is significant is a matter of debate. A third of men will not notice any symptom improvement at all (EUA 2006: 36). Within the Swedish guidelines for BPH, alpha-blockers are said to reduce the symptom bother slightly and increase the flow rate slightly better than placebos (SBU 2011: 321). The results are statistically significant but rather small (SBU 2011: 335). And, as the EUA guidelines suggest, not only are there are very real placebo effects to take into consideration (EUA 2006: 35), but there is always a publication bias to statistical evaluations based on published studies; unsuccessful studies do not tend to be published (noted in the Swedish guidelines, too). For example, of all the published studies that the SBU report found to evaluate, none had been financed by independent sources; all were funded by the pharmaceutical industry (SBU 2011: 317f). They suggest that it is important to remember that scientific and commercial interests have influenced the design, conduct and evaluation of the studies upon which conclusions about alpha-blockers are based (SBU 2011: 325).

Related to the use of alpha-blockers, and despite the lack of initial success with hormone treatments in the early twentieth century, hormones are also used today to treat LUTS/BPH. But rather than tracing their genealogy to the early experiments with castration or the testosterone excitement of the 1930s, the use of 5-alpha-reductase inhibitors (5-ARIs) stems from an observation made in 1968 that the active androgen in the prostate gland was not testosterone but dihydrotestosterone, which is made when the testosterone breaks down with the help of the enzyme 5-AR (SBU 2011: 345).

The decision to use 5-ARIs, either by themselves or as part of a combination treatment with alpha-blockers, depends on the size of the prostate. This is determined, according to the AUA, by prostate volume measurements and the prostate-specific antigen (PSA), and the AUA recommends discussing the relationship between PSA and prostate size with the patient (AUA 2010: 29). The EAU recommends using 5-ARIs for prostates larger than 40 mL (EAU 2006: 31). The hoped-for result is a shrinkage of the prostate by 15–25 percent and a decrease in PSA value of 50 percent (AUA 2010: 29). Again, the same barrage of tests is used to determine treatment success. Large clinical trials seem to suggest that they can shrink the prostate by 20–30 percent, improve symptom questionnaire scores by 15 percent and moderately improve the urinary flow rate (EUA 2006: 30). This improvement in peak-flow rates is claimed to be significant when compared to placebo (AUA 2010: 31), though, as with the alpha-blocker discussion, the use of the term “significant” is not the same as suggesting a substantial improvement. A statistically significant, but small, effect is achieved with 5-ARIs (SBU 2011: 361). And, again, as the Swedish policy document notes, all the studies that they deemed to fulfill a decent scientific standard for consideration were actually financed by the pharmaceutical companies who produced the drug being studied (SBU 2011: 349).

Some side effects were, however, experienced from 5-ARIs; the most well known were repression of sexual function (erection and ejaculation) and sexual desire. There have also been studies reporting a 3 percent incidence of prostate cancer with finasteride, one of the 5-ARIs on the market (AUA 2010: 31).

Sometimes men will be prescribed both alpha-blockers and 5-ARIs. Combining the 5-ARI treatment with alpha-blockers is done in part because the alpha-blockers generally have a relatively immediate effect while the 5-ARIs can take a while (up to several months) to begin working. Thus the patient can notice an improvement right away and also, hopefully, start a medication that will eventually reduce the size of his prostate. This is particularly recommended for men with large prostates. Both symptom and peak-flow rates seem to be improved with a combination therapy, that is, combining alpha-blockers and 5-ARIs, but this combination therapy also seems to increase the severity of side effects (AUA 2010: 34). The Swedish evaluation of combination therapy even suggests that the increased side effects may call into question the benefits of combination therapy (SBU 2011: 381).

2 Intra-acting Actants

I came to the question of treatments for LUTS/BPH from a background in feminist science studies, and a particular interest in how feminist critiques of medicine have conceptualized the body. I take inspiration from early grassroots critiques of the medicalized female body, as epitomized by *Our Bodies, Ourselves* (Boston Women's Health Book Collective 1973; see also Davis 2007), which question the ontological basis of medical knowledge. Additionally, academic critiques of sex and gender in science as popularized by Emily Martin's famous article "The Egg and the Sperm" (1991), Jordanova's history of anatomies (1999) and Fausto-Sterling's book *Sexing the Body* (2000) have colored my readings of the medicalized prostate. My work also draws on the turn to seeing male bodies also as bodies with gendered and sexual expectations ascribed to them by a medical discourse, rather than merely the universal, neutral body of medicine (Marshall 2002; Oudshoorn 2003; Tiefer 2006).

This background has inspired me to approach LUTS/BPH treatment options in the clinical guidelines through an agential realist lens (Barad 2007). Doing so helps me see how various LUTS/BPHs and prostates are enacted as knowledge phenomena in the clinical guidelines, and with what medical and technological tools the diagnoses of LUTS/BPH are made. A useful tool for this is Barad's term "intra-action." Barad writes, "*observations do not refer to objects of an independent reality*" (Barad 1996: 170, emphasis in original). It is not possible to say that the object exists, as we know it, outside of or separate from the person doing the knowing. Rather than saying that a person and a thing "interact," we should talk about them intra-acting and thereby remind ourselves continuously that the person and the thing are both implicated in the process of creating the knowledge that is then used to define the thing. Barad posits that *concepts are defined by the circumstances required for their measurements* (Barad 1996: 169) and that "*phenomena are constitutive of reality*. Reality is not composed of things-in-themselves or things-behind-phenomena, but things-in-phenomena … What is being described is our participation *within* nature" (Barad 1996: 176, emphasis in original). Within this framework one has to consider phenomena the basic unit of existence, not subjects and objects. "That is, phenomena are ontologically primitive relations—relations without pre-existing relata" (Barad 2003: 815).

I use Barad's term "intra-action" to see the details and actants involved in the knowledge phenomena used to create a LUTS/BPH treated by alpha-blockers. Intra-action signifies that the thing being known cannot be separated from the way, the practice or the apparatus that makes it known. This is in contrast to the more common term "interaction," which reinforces the separateness of the object and the method of observation (Barad 1998: 96). Intra-action reflects Barad's dismissal of representationalism. Barad suggests that the referent and the apparatus of observation (and, by extension, the person doing the observing) become intra-acting subunits of a phenomenon, all of which are necessary components for the phenomenon to be observed. What is described by the observations is not nature, but the intra-active participation of all the subunits (Barad 1998: 105). Analytically, the term "intra-action" becomes useful because it articulates the local, specific practices involved in making what Barad calls agential cuts, or the material-discursive cuts that produce "objects" from knowledge phenomena. It provides a way of analyzing the details in knowledge practices. Thus, the phenomenon of knowing a lower urinary tract symptom or of knowing the prostate involves both the urination symptom and the prostate, but also the way of knowing it and the person doing the knowing. Within this theory of knowledge, one cannot separate out the prostate or the bladder from the way it is examined and the doctor doing the examining, or the patient presenting with the symptom, or the ultrasound creating an image of the bladder and so on; there are many different elements within each phenomenon of knowledge, and these must be considered analytically.

This is useful for thinking about LUTS/BPH because intra-action allows one to show how knowledge about LUTS and knowledge about BPH are built out of smaller blocks of knowledge about urination and the prostate, and responses to treatments, but also that those smaller blocks of knowledge are "phenomena of knowledge," not merely facts about parts of the body and how they work. And, as such, it is necessary to understand who and what else is continuously involved in the practices of creating that knowledge, especially during the examination and diagnostic practices and when those same phenomena create knowledge again about the success of the treatment.

Questions about the political implications of how bodies, diseases and subjectivities are constructed, enacted and defined are commonly found in feminist studies of science, and very often in the studies which have taken women's bodies and health-care practices as their empirical field (Laqueur 1990; Martin 1992; Oudshoorn 1994; Fausto-Sterling 2000; Das and Addlakha 2001; Åsberg and Lum 2010). Some of that work has gained inspiration from (and criticized) earlier discussions about materiality found in Actor Network Theory (ANT) (see Dugdale 1999; de Laet and Mol 2000; Law and Singleton 2005: 347). But ANT has some useful terms and concepts for this study, too. Two that provide a background to this chapter's understanding of technology and the social are the concepts of *symmetry* (the challenge to analytically consider both the human and the nonhuman as part of the social) and *actant* (a term used for both humans and things in a network of actors, making it easier to consider both in an analysis) (see Law 1987; Latour 1999).

I am going to be using the term "actant," applying it to both human and nonhuman elements of the intra-actions that constitute the various knowledge phenomena explored in relation to pharmaceutical treatments of LUTS/BPH. I am using "actant" to remind myself and the reader that I assume an analytical symmetry between the human and nonhuman elements, thus I want to avoid calling human actants "actors" and nonhuman actants "things." Rather, by calling them all "actants," their respective actor and thing status is both called into question and opened up for an analysis of who or what is granting these subject positions to them; who or what is granting the various elements the agency to say something about LUTS/BPH.

Actant has some very useful baggage, baggage that makes it a valuable theoretical and methodological term for really exploring the politics enrolled in a human or nonhuman subject or object, in a way which Barad's "material-discursive cut" is not (yet) capable of. Examples of this can be found in *Pandora's Hope* (Latour 1999), with its entourage of person/guns, sleeping policemen, chimps with sticks, and overhead projectors, and where terms like "translation," "articulation," "delegation," "the folding of time and space," "symmetry" and "black boxes" give voice to the politics of networks within actants (see also the discussion of door closers in Latour's (1999) and Callon's (1986) discussion of actor-worlds). Latour argues for the use of *actant* rather than *agent*, because it allows collectives and associations of actants (Latour 1999: 180, 182). Perhaps this is even better expressed with the term "hybrid *collectif*" (Callon and Law 1995). Both *collectif* and associations of actants allow for the conceptualization of distributed agency, done relationally, which is also an important concern of many agential realist analyses.

Discursive cuts point to how the objects are "made" within the knowledge phenomenon, but actant does both this (e.g., with black boxing in the early work or the concept of bracketing in Mol 1999, 2002) and provides a toolbox for discussing what, who and to some extent how, when and where values and actors are involved in the material-discursive cut. Or, as Latour claims,

> [W]e do not live in a society gazing out at a natural world or in a natural world that includes society as one of its components. Now that nonhumans are no longer confused with objects, it may be possible to imagine the collective in which humans are entangled with them. (Latour 1999: 174–175)

The use of actant will allow me to develop, as Suchman points out is important, "a discourse that recognizes the deeply mutual constitution of humans and artifacts, and the enacted nature of the boundaries between them, without at the same time losing distinguishing particularities within specific assemblages" (Suchman 2007: 260). It is with this goal in mind that I am combining actant with Barad's agential realism. Barad asserts that

> [t]he agential realist understanding that I propose is a non-representationalist form of realism that is based on an ontology that does not take for granted the existence of "words" and "things" and an epistemology that does not subscribe to a notion of truth based on their correct correspondence. (Barad 2007: 58)

However, I argue that once the material-discursive cuts are made those "words" and "things"—those actants—are active/granted agency, and examining their participation is valuable. And it is at that point in the cutting that I direct my analysis—once things like prostates, alpha-blockers, urine and measuring cups have become knowledge phenomena.

3 Pharmaceuticalized Prostates

Some claim that alpha-blockers have the ability to treat an enlarged prostate. I claim that they (simultaneously) create a pharmaceuticalized prostate.

The concepts of actant and intra-action provide tools to see how objects of knowledge about a specific disease and treatment method are constructed as collectives of actants intra-acting together. The pharmaceuticalized prostate is complex. It has had a long history of treatments throughout the twentieth century that led to the work with alpha-blockers, traceable in a way similar to Oudhourn's work on the genealogy of hormones (Oudshoorn 1994, 2003). Examining the genealogies of actant *collectifs* creating knowledge about the project, and tracing them back beyond the obvious actants, can be useful for understanding why specific actants are more assertive within an intra-action than others, and how they enroll (or not) the weaker actants into their own knowledge phenomena. In the case of alpha-blockers, the fact that these guidelines rely on a standard view of knowledge that evaluates study results against the gold standard of RCTs and the practices of EBM results in a stronger case for alpha-blockers than herbal treatments. As the Swedish guidelines mentioned, there is little pharmaceutical funding available for large-scale RCTs of stinging nettles or pumpkin seeds, so potential benefits of these treatments are not included in the guidelines. Research shows the importance of the details of innovation processes of new drugs and the clinical trial practices used to test, approve and promote them (Jonvallen 2005; Sjögren 2006; Helgesson 2010), as well as the actual marketing strategies used to sell them, both to doctors and to patients (Healy 2004; Moynihan and Cassels 2005) and the role profit interests have in these. Yet even though the alpha-blockers have been accredited as the agency to (sometimes) treat enlarged prostates, they have not been universally successful. There is still some debate about when and how surgery should be used instead of pharmaceutical treatments (Johnson 2016). Returning to Suchman's work on agency and her insistence that it is important to consider what happens when an object is granted agency (Suchman 2007), my analysis hints at the details of agency granting and the ways it is relevant that agency is given to nonhumans—in this case the alpha-blockers. It prompts one to ask why agency is being attributed to a pharmaceutical, and who or what has an interest in claiming that alpha-blockers are a potentially successful treatment for LUTS/BPH. Specific knowledge claims are made through these, knowledge claims which can strengthen or diminish the relative position of general practitioners, urologists, surgeons and pharmaceutical interests.

The *collectif* of actants in an alpha-blocker prostate includes more than humans and their professional or commercial interests. This can be seen clearly in the practices of knowing the prostate. The treatment or management of LUTS/BPH is the continuous doing of a knowledge phenomenon. Understanding it as such conceptualizes a treatment or management technique as an iteration of diagnostic practices. It levels the analytical field between the ingestion of the alpha-blockers and the use of ultrasound, the digital rectal exam, symptom questionnaires and peak-flow charts, viewing them as both equal and the same type of practice within medicine.

These inscription devices produce different, multiple, LUTS/BPH prostates which need to be coordinated—enacted as a cohesive object (Mol 2002)—to become a single anatomical part with a disease to be treated. These iterations of measuring-treating, measuring-treating continually associate the alpha-blockers, the size of the prostate and urination. Erasing a distinction between otherwise separate "diagnostic" and "treatment" practices shows the practice of treatment as actually part of the diagnostic flowchart, even if it is not labeled as such. Treatments can, through this analysis, become another iteration of a diagnostic test. Does the patient respond to the alpha-blockers? In that case, he can be said to have LUTS/BPH. Does the patient not respond to alpha-blockers? In that case, he can be put on 5-ARIs. If he responds to this, he can still be said to have LUTS/BPH. The alpha-blockers and the 5-ARIs, along with the other diagnostic actants in the network like the questionnaire and the peak-flow measurements (and the respective actants in their network), become an intra-acting collective, a network of heterogeneous actants, to diagnose yet again the patient's LUTS/BPH, and to move the patient along the flowchart of diagnosis/management. And together with the alpha-blockers and 5-ARIs, this rich *collectif* produces the knowledge phenomenon, the pharmaceuticalized prostate.

The prostate plays an essential role in this intra-action, since its shrinkage will be part of what determines if the pharmaceutical treatment is considered successful. To understand it in this way, though, requires one not to think of the prostate as a separate, ontologically preexisting entity, but rather a phenomenon of knowledge itself and, in this case, a phenomenon of knowledge that says something about a dynamic size. It is not the prostate alone but rather the prostate as measured (probably by an ultrasound) both before and after the treatment is initiated. Thus the measuring is necessarily complemented by the concept of time and change, adding a dynamic aspect to the knowledge phenomenon's intra-action. In this medical paradigm, prostate sizes, peak flows and symptom questionnaires are relevant to LUTS/BPH, rather than other ways of knowing the urination system.

Even though the alpha-blockers and the 5-ARIs are nominally labeled as management or treatment methods, they are also creating specific LUTS/BPH knowledge phenomena through their use, the same way that the various diagnostic methods do. They are as much diagnostic (in the sense that they confirm the patient's position in the LUTS/BPH flowcharts and as a relevant participant within the LUTS/BPH discourse) as ultrasound measurement. The use of "treatments" to confirm or deny a diagnosis is not new within medicine—or outside of it. Within general practice medicine today, antibiotics are often prescribed long before bacterial cultures produce the answer as to whether or not a patient has a bacterial infection. And the diagnosis of even more serious diseases has long been confirmed or discarded based on how a patient has responded to a treatment or medicine. For example, a patient's response to iron pills was used to diagnose blood deficiency and anemia in the 1930s and 1940s, rather than the use of hemoglobinometers and hemocytometers (Wailoo 1999: 40–41). By not considering a disease an ontologically preexisting condition and instead insisting that it is continuously created in response to treatment, the analysis of that knowledge phenomenon shows how the various treatment and diagnostic practices are leveled, at least analytically, even if it does not appear so to the patient in clinical practice.

Advertisements for alpha-blockers show men doing things which take time, like playing chess, or which don't allow frequent access to a toilet, like white-water rafting, which also plays on the presence of running water. These images speak to the annoyance that men experience from frequent urination urges. Another poignant advertisement shows an older man driving on a country road in a blue convertible car with a lovely woman in the passenger seat—all standard North American masculinity symbols—but towing a trailer with a port-a-potty on it behind the car (see Chaps. 5 and 6 for a closer analysis of pharmaceutical advertising analyzed through a gender-sensitive lens). Medical studies of life with LUTS/BPH have also reproduced understandings of masculine practices. One of the most commonly cited longitudinal studies is the Olmstead study, which asks men to think about urination practices in relation to other, "normal," activities like golf, theater shows, movies and car trips. Seeing these cultural practices appear in advertisements and medical studies presents the prostate as closely associated with specific masculine practices, in an analytical approach that draws on feminist work on the medicalization of female bodies and subject positions.

The alpha-blockers themselves are very important actants, both the pills and their production networks. The pills can be queried on many levels: what does it mean to look for "health" when "health" is defined as involving medicated urination with minimal or at least tolerable side effects? And this concept of "health" requires a pill that is ingested daily for the rest of one's life. What sort of understandings of health and the healthy subject position are created by this practice? A "healthy" subject urinates unhindered but needs medication. And how are these ideas promoted to the patient and the doctor, both through the form of the pill (the physical shape, its ease of swallowing rather than a need to be injected or topically applied), that it is strong enough, with a long enough half-life to be ingestible and practical, that it is something that can be purchased easily, stored at home, stashed in a suitcase for trips, commonly available within a network of pharmacies so that it can be prescribed to a large group of patients and taken when needed. In some ways, a lot of work is delegated to the medication. And as it is allowing unhindered urination in a context of disease, it is being delegated the work of a catheter or a surgeon, making them unnecessary for the act of peeing.

Beyond the pills themselves, there are the doctor and the patient, also actants in their respective roles, and the prostate, which is very relevant for the use of alpha-blockers, since it is the target of their action. Together, as a *collectif*, they work to target the prostate and monitor its response. Likewise, the tools that determine the size of the prostate, like the ultrasound and PSA test, and their black-boxed networks are also relevant, given that the decision to try treatment of LUTS/BPH with alpha-blockers is partly dependent on the estimated size of the prostate. Then there are the networks involved in measuring the results of the treatments—the symptoms questionnaire and the peak-flow charts, and so on—so the urination practices and bothersome aspects are also actants involved in this. Various inscription devices are used to turn the temporal practices of urination into stable numbers and graphs that translate the urination into "facts" (i.e., truths that are done, made, created and sustained in scientific practices) about the prostate. Two elements—change and time—are also relevant; and to consider them more closely involves asking how they are enrolled in the network of intra-acting elements. For example, the change in the prostate size must first be inscribed and translated in the ANT sense (Latour 1999) into a number which can be both recorded and considered as well as compared with a new size later. Change is enrolled through a process that includes iterations of inscription and translation. Time, as well, must somehow be quantified, at least roughly, so the distinction between the quick response time of an alpha-blocker and the slow response time of a 5-ARI can be contrasted, and so that sufficient passage of time can be measured before discontinuing treatment because the patient experiences no change at all.

The side effects are part of this *collectif*, as well, which enrolls concepts of masculinity and sexuality into the network of intra-acting actants. Men taking alpha-blockers and 5-ARIs are likely to experience reduced desire and erectile dysfunction. Because of this, it is not unusual for a man to also receive a prescription of Viagra in conjunction with treatment for LUTS/BPH. The identification of these side effects, their recognition as a problem and their subsequent treatment with an additional little blue pill is an example of how the pills are refracting cultural expectations of masculine sexuality. The unspoken norm that is refracted through the pill is that if a man loses his desire to have sex, he can be medically treated.

Recognizing these various actants and their inscriptions, delegations and translations can help analyze relational practices being enacted within the networks and between the intra-acting actants in the knowledge phenomenon "pharmaceuticalized prostate."

In this chapter I have named some of the actants which are relevant within the intra-active networks for knowing the LUTS/BPH through alpha-blockers. But though these intra-acting actants are all necessary, they are not necessarily all working together on equal terms. The marketing of targeted alpha-blockers specifically for LUTS/BPH, for example, can influence the choice of pharmaceutical made by the patient and/or his doctor. More relevant to the analysis done here is that one can see that the publications created by and released from the clinical trials which, as the SBU report noted, have been financed by the pharmaceutical companies, are also relevant actants for the decision to use/treat/manage/know LUTS/BPH through alpha-blockers. Their "facts" about the results of treatment with various types of alpha-blockers influence the knowledge about this method of treating/knowing LUTS/BPH in clinical guideline documents like the ones analyzed here, which then also influence how the patient–doctor–alpha-blocker–prostate knowledge phenomenon can be constructed through the prescription and use of alpha-blockers.

Many actants are enrolled in the pharmaceuticalized prostate knowledge phenomenon, both obvious, visible actants like the doctor, the prostate, the peak-flow charts, and less obvious, more invisible actants, like the publication practices for clinical drug trials. Between them are imbalances of power which let some more than others dictate what a diseased prostate is and how it should be treated. For example, the diagnosis and treatment flowcharts whose boxes and lines lead to alpha-blocker treatment seem, when deciding on alpha-blockers, to give precedence to tests that can say something about the size of the prostate rather than information about the man's diet or sexual practices during this knowledge phenomenon. Thus, specific tests and their actant networks (digital rectal exam, the transrectal ultrasound and the PSA test) allow one element (the prostate as known through them) to define knowledge creation in the relational, pharmaceuticalized prostate knowledge phenomenon in specific ways. The size of the prostate and its eventual response to the alpha-blockers are given the power to define how the knowledge phenomenon is perceived, experienced and evaluated by the patient and his doctor. But the agency to enact the pharmaceuticalized prostate as a successful treatment is distributed across the relations of the prostatic tissues and their measurement by inscription devices, the pharmaceuticals and their ability to be consumed regularly, the man and his compliance with the pharmaceutical regime, as well as his experience of reduced worry from LUTS/BPH. The production of a successful (or failed) pharmaceutical treatment is a relational intra-action of the pharmaceuticalized prostate.

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4

New Puberty; New Trans: Children, Pharmaceuticals and Politics

Celia Roberts and Cron Cronshaw

> Oxytocin, serotonin, codeine, cortisone, the estrogens, omeprazole, testosterone, and so on, correspond to the group of molecules currently available for the manufacturing of subjectivity and its affects. We are technobiopolitically equipped to screw, reproduce the National Body, and consume. We live under the control of molecular technologies, hormonal straitjackets intended to maintain biopower: hyperestrogened bodies-rape-testosterone-love-pregnancy-sex drives-abjection-ejaculation. And the state draws its pleasure from the production and control of our pornogore subjectivity. (Preciado 2013: 118)

> Biomedicine is at the forefront of the contemporary biopolitics of sex, gender, sexuality, and race … and the transgender child is emerging as one of its newest anchors. (Gill-Peterson 2014: 412)

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Gonadotropin-releasing hormone (GnRH) analogue therapies allow clinicians to prevent the onset of pubertal development by intervening in hormonal messaging between the brain and the gonads. These therapies are used in early developing children to hold off so-called precocious puberty and to normalize the timing of sexual development (development recommences when treatment ends) (Roberts 2015). Although still an off-label use, they are increasingly also used to delay puberty in children who identify as trans. Hailed by clinicians, parents, therapists and trans young people and adults as a lifesaving option, GnRH analogues have the potential to change transgendered experience across the life course. Children who never experience puberty as their assigned sex at birth can, it is argued, transition in new and more complete ways as teenagers, in part because the hormonal medications used to transition will have different effects on undeveloped bodies (compared to their historic effects on physically mature adult bodies) and in part through avoiding the psychological suffering involved in living through unwanted sexual development.

This chapter analyzes a range of discourses describing the use of GnRH analogues in trans children, exploring how new "trans child" subject positions are brought into being in material-discursive encounters with these medications. The prescription and taking of GnRH analogues, we argue, constitute a new form of "sexing." The discourses we explore are found in clinical publications and guidelines, patient/parent activist websites, vlogs, and online and broadcast media (magazines, television documentaries and newspapers). Our analysis of these discourses underpins a broader argument about the multiple ways in which pharmaceuticals are interwoven with politics that questions the usefulness of the term "pharmaceuticalization" to describe this process. Far from neutral technologies, GnRH analogues are entangled in the production of new forms of subjectivity and life/experience that are unimaginable without them. They are, to quote Paul Preciado, part of "the group of molecules currently available for the manufacturing of subjectivity and its affects" (Preciado 2013: 118). In specific ways they also manufacture sex. Here we ask: what questions does this "era of puberty suppression" (Roen 2011: 58) open up around sex/gender, pharmaceuticalization and the ethics of intervening into children's bodies?

Before we start we want to clarify our use of terms. We use "children" and "child" to refer here to pre-teens and "young people" to refer to those in their teens. We think it is important to retain the use of the word "child" when discussing puberty blockers, as puberty (and thus the timing of puberty-blocking medication) now frequently begins before children reach their teens (Roberts 2015). The terms "transgender," "transsexual" and "trans" are more complicated. For us, "transsexual" and "transgender" have notably medical overtones, so we avoid them here except when citing others. We use the shorter term "trans" in order to resist the distinction between sex and gender that is implicit in both alternatives. In this chapter we also avoid the medical terms "gender identity disorder" and "gender dysphoria," again using the simpler and less medical "trans" to refer to a wide range of possible embodiments.

1 Early Feminist Work on Medicine and Trans Subjectivities

In their early historical accounts of patriarchal Western medicine, Barbara Ehrenreich and Deidre English point out the troubling fact that feminists both criticize much medical thought and practice (finding them sexist, classist and racist) and demand more access to them:

> As feminists we are totally antagonistic to the medical system as a source of sexist ideology. But at the same time, we are totally dependent on medical *technology* for some of the most basic and primitive freedoms we require as women—freedom from unwanted pregnancies, freedom from chronic physical disability. (Ehrenreich and English 1973: 87, emphasis in original)

This dependence, they astutely argue, increases the power of sexist medical institutions: "They have us, so to speak, by the ovaries" (Ehrenreich and English 1973: 87). Ehrenreich and English's proposed solution focuses on quality rather than quantity of services. In the spirit of their temporal and spatial location, they endorse self-help as "an attempt to seize the *technology* without buying the ideology" (Ehrenreich and English 1973:

88, emphasis in original), emphasizing the inherently critical style of collective feminist self-help and activism (e.g., focusing on class and racial differences among women).

Although under-theorized, the distinction drawn here between technologies and bodies is key to their argument and, as we will show, to our own. Importantly for us, Ehrenreich and English also raise questions about women's felt "needs" for medical interventions: "How much of our 'need' is manufactured, and how much is real?" (Ehrenreich and English 1973: 91). Rightly, they point out the strong ambivalence within women's health movements on this question (the medicalization of birth provides one ongoing area of debate). Fundamentally, they suggest, women living in patriarchal cultures cannot know our "'real' needs, our 'real' strengths and liabilities … any more than there is a way to understand what 'female nature' may really be" (Ehrenreich and English 1973: 92). Easier to adjudicate are questions of power and control; who gets to decide what treatments are available and for whom. Feminist politics, in their view, should be about challenging sexist forms of control of "social options" and the "institutions of society that now define those options" (Ehrenreich and English 1973: 93) rather than defining women's health per se.

Ehrenreich and English's focus on technology is highly pertinent to considering trans issues. Although not discussed in their 1973 book, the availability of medical technologies to change genders was the subject of much second-wave feminist debate. Famously, radical "feminist ethicist" Janice Raymond regarded "the transsexual" as a sign of society's anti-feminism (Raymond 1979: 1). In *The Transsexual Empire* (1979), Raymond developed a political critique of the patriarchal medical system, arguing that "a society that produces sex-role stereotyping functions as a primary cause of transsexualism" (Raymond 1979: xvii). The main focus of her analysis is thus male to female transsexuals: "transsexualism was developed by men for men" (Raymond 1979: xxi). Raymond (1979: 120) argues that "The medical model is at the heart of the transsexual empire," suggesting that treating transsexuality as an individual medical/psychological issue means that "many moral issues, as well as sociopolitical, economic and environmental problems are transformed into technical problems. This also means," she adds, "that critical awareness, choice and responsibility are not perceived as 'curative' but are replaced by technical 'cures'" (Raymond 1979: 120–121). As long as there continues to be an emphasis on transsexualism as a health issue requiring medical intervention, in her view, barriers to "genuine transcendence of the transsexual problem" will exist (Raymond 1979: 2).

Raymond (1979: 10) takes an essentialist approach to sex, highlighting chromosomal sex from John Money's (1969: 91–93) list of six sexes as the element of sex not open to manipulation. Trans people's use of hormonal therapies, in her view, produces harm because it interferes with a bodily integrity that flows from chromosomes via endogenous hormones:

> The chromosomal basis of maleness and femaleness is one defining factor of *bodily* integrity. Chromosomes contribute to bodily integrity and one clue is that transsexuals must continually suppress their anatomical and morphological consequences by estrogen and androgen therapy. Yet my appeal here is not that chromosomal maleness or femaleness is natural. Rather, I am emphasising that medicalized intervention produces harmful effects in the transsexual's body that negate bodily integrity, wholeness and be-ing. (Raymond 1979: 18)

Like Ehrenreich and English, Raymond relies on an ontological separation of science and nature, the body and technology. Consequently, as Gill-Peterson (2014: 405) writes, the trans body is figured here as "passive, inaccessible and ultimately separate from the subjectivity that is meant to be its anchor," that is, one's "psychological sex." Modification of such a preexisting body gives rise to unfavorable comparison with "natural" or "typical" bodies.

Sixteen years later, Bernice Hausman (1995), in her now well-cited *Changing Sex: Transsexualism, Technology and the Idea of Gender*, criticized earlier feminist writings such as Raymond's for not paying enough attention to medical technologies. Hausman departs from earlier feminists who approach "woman" as a natural and axiomatic category by emphasizing the role of technology in producing transsexual subjectivity. Whereas Raymond (1979: 175) views transsexuals as the "medicalized victims" of western society's gender codes and treats technology as an "effect of male domination" (Hausman 1995: 13), Hausman argues that the role of technology is important not only in an ideological sense (as a patriarchal tool) but as a "signifier of ideological and *material* proportions" (Hausman 1995: 12, emphasis added). Technologies both make "changing sex" a material possibility and play a role in delineating sexological classifications and, therefore, subject positions. For Hausman, "Medical technologies directly address this resistance of the body and, by changing the body's capacity to signify sex, affect the potential relation of the body to what are known as gender ideologies" (Hausman 1995: 14).

Writing three years before Hausman, in *The Empire Strikes Back: A Posttranssexual Manifesto* (1992), trans woman and lesbian-feminist Sandy Stone highlighted the way in which many trans people feel the need to present a "correct" personal history in order to secure hormonal and surgical intervention from the medical profession. Omitting details of experience such as sexual habits and adhering to a "sanctioned" version of transsexual subjectivity may increase the chances of securing medical assistance, Stone argues, but comes at the cost of recognizing "intertextuality" (i.e., the "multiple permeabilities of boundary and subject position") (Stone 1992: 166). Stone urges trans people not to omit aspects of their experience, encouraging them to forgo passing,

> to be consciously "read", to read oneself aloud—and by this troubling and productive reading, to begin to write oneself into the discourses by which one has been written in effect, then, to become a (look out—dare I say it again?) posttranssexual. (Stone 1992: 168)

For her, these are important steps toward unsettling the cultural ascendancy in narratives of gender. Indeed, Stone (1992: 164) suggests that speaking honestly of trans experience articulates a position outside binary gender discourse.

Hausman concurs with Stone when she notes the limitations that demands for particular trans stories impose on the making of transsexual subjectivity (Hausman 1995: 143) but argues that Stone fails to explore the ways in which research with transsexuals played a part in producing the category of gender. If one considers this, then it does not make sense to suggest that transsexuals are speaking from "beyond the gender binary" (Hausman 1995: 144) or, as Stone writes, "outside the boundaries of gender" (Stone 1992: 295). When Stone encourages trans people to speak from beyond the gender binary, then, she is, according to Hausman, forgetting that the concept of gender was produced through research on transsexualism, which therefore situates the transsexual voice *inside* the discourses of gender:

> The production of the concept of gender within research on intersexuality and transsexualism suggests, however, that the transsexual subject speaks fully *within* the cultural discourse of/on gender, not only because that discourse was produced precisely to account for intersexual and transsexual subjects' experiences, but also because the performance of transsexual subjectivity depends upon the expert manipulation of traditional gender codes. To be a transsexual is perhaps to be "in gender" more fixedly than other subjects whose gender performances are perceived to be "natural." (Hausman 1995: 144)

Hausman is somewhat positive about what she calls "partial technological sex change" (1995: 195), suggesting that these highlight the resistance of the body to social norms of sex/gender (1995: 199). Such points of resistance—*rather than multiplying gender performances*—are, she argues, the best route for destabilizing the existing gender system:

> We need to account for those points at which discourse cannot describe or regulate the body's significations, to understand how theory cannot appropriate the body as its signifier…. We can read the body's resistance to "gender"—legible for instance, in plastic surgeons' continuing difficulty in constructing penises and in the medical silence surrounding problems with vaginoplasty or the long-term effect of using massive doses of sex hormones. (Hausman 1995: 200)

Hausman's debate with Stone, and indeed later elaborations and criticisms of Hausman (Prosser 1998; Alamilla Boyd 2006; Spade 2006; Heyes 2007), to our minds speak to the core dilemma identified by Ehrenreich and English: how is it possible to both inhabit and resist—to be made within and refuse—sexist medical cultures? What kinds of speaking and action might open space to contest limiting figurations of sex/gender even while we necessarily are figured by them?

2 Contemporary Trans: Theorizing the Guinea Pig Self

More recent work on trans challenges any reliance on a concept of underlying or natural sex. In a move to counter the potential for transphobia in human-centric accounts, for example, Julian Gill-Peterson (2014) uses Bernard Stiegler (1998) to champion trans as "an expression of the originary technicity of the body" (2014: 406). Here hormone therapy is figured a "participation in the technical capacity of the endocrine system" (Gill-Peterson 2014: 407). In this line of thinking, trans bodily modifications do not constitute a betrayal of the body's naturalness but instead as "participation in the body's open ended capacities" (Gill-Peterson 2014: 407; see also Stryker and Sullivan 2009). Charting various circulating hormones (through the human body, the apparatus of institutional health care, legal and illegal markets, the environment) Gill-Peterson concludes that "not all of these itineraries are enabled by human action or even by the unintended effects of human agency" (Gill-Peterson 2014: 430), meaning that hormones should be regarded in terms of their dynamism and not simply thought of as "domesticated tool[s] synthesized and used by humans for irrational and rational ends" (Gill-Peterson 2014: 403). The trans subject in this account becomes

> an artisan, and the material with which the subject is engaged is the flesh of the body, with the hormone molecule serving as the interface relating the two without opposing them or collapsing their distinction. The body is not a passive substrate ruled by a transgendered consciousness but an open technical system with its own implicit forms, its own affects that enable and restrict the capacity of the subject to change the body with hormones. (Gill-Peterson 2014: 408)[1]

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[1] Using Donald Winnicott's theory of the "True" and "False" Self, Diane Ehrensaft (2009) makes a very different argument, suggesting that using puberty-blocking medication can allow young people to express their gendered True Self, that which they experience themselves to be. While this is not an argument for a biological account of gender, it does separate the experience of self from the technicity of hormonal medications.

Preciado's (2013) memoir of experimenting with sex/gender and sexuality through testosterone provides a first-person narrative of this artisanal work. In this both highly theorized and sexually explicit book, Preciado argues for a new "copyleft gender politics" based on "the principle of the auto-guinea pig" (Preciado 2013: 398).[2] Injecting oneself with hormones and voluntarily engaging with sexual surgery certainly has a rich history: Eduard Brown Sequard's self-injection of guinea pig and dog testicles, and Sigmund Freud's "Steinach operation"—both attempts to stimulate aging male bodies—are well-known cases in point (Roberts 2007). Preciado brings such experiments into the contemporary age, arguing that the objective of using black market hormones is "The transformation of the body of the multitude into an open living political archive: the common *somathéque*" (Preciado 2013: 389).

The neologism *somathéque*—referring "to somatic technologies and to the body as techno-living archive, as in the word *bibliothéque*" (Preciado 2013: 389)—captures Preciado's orientation toward the body as performative techno-object. Although a memoir of powerful emotions and desires, psychological interiority is not analytically explored here. Such exploration, Preciado concludes, following Felix Guattari, is better done in collective (and then public) bodily action than in text. In a section on the power of drag king workshops to expose, undo and learn embodied sex/gender practices, Preciado writes:

> After having experienced a variety of psychoanalytical or psychodynamic therapies, I have come to understand the drag king workshop as a new practice of political therapy, part of an array of techniques of criticism, reprogramming, and psychopolitical care that we might call *queeranalysis*. (Preciado 2013: 378)

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[2] Biopolitical copyleftism seeks to wrest power away from the regulatory capitalist clutch of pharmaceutical companies and the state, which manage access and administration of sex hormones through legislation and transition protocol, to generate a system which allows biocodes to be freely used, distributed and modified. Artist Ryan Hammond's *Open Source Gendercodes* campaign (http://opensourcegendercodes.com/projects/osg/) is a recent example of copyleft queer activism; funding is being sought to develop a transgenic tobacco plant that can be cultivated at home by members of the public, thus leading to the deregulation of hormones, such as testosterone and estrogen.

While Preciado politically fiercely resists individualization, the book is generically self-centered. Composed in autobiographical diary style, it throws readers into an intensely private world of love, sex, friendships and music that uses initials to refer to friends and provides detailed accounts of daily life and movements as well as sexual encounters. In many ways the book feels like an internal conversation; a set of clever, highly informed, sometimes vitriolic or enraged rants. In the penultimate section, however, Preciado addresses readers directly, summarizing his aims in documenting the daily experiments with testosterone:

> In order to accomplish the work of therapy for the multitudes that I have begun with these doses of testosterone and with writing, I now need only to convince you, all of you, that you are like me, and not the opposite. I am not going to claim that I'm like you, your equal, or ask you to allow me to participate in your laws or to admit me as a part of your social normality. My ambition is to convince you that you are like me. Tempted by the same chemical abuse. You have it in you: you think that you're cis-females, but you take the Pill; or you think you're cis-males, but you take Viagra; you're normal, and you take Prozac or Paxil in the hope that something will free you from your problems of decreased vitality, and you've shot cortisone and cocaine, taken alcohol and Ritalin and codeine… You, you as well, you are the monster that testosterone is awakening within me. (Preciado 2013: 398)

"Chemical abuse" here underpins a human commonality: we are all tempted to take something, experiment somehow, with our sex/gender, our sexuality, our feelings of happiness and desire. For Preciado, this is the micropolitics of our times, dubbed "the Pharmacopornographic Era." Such practices, the book argues, are constitutive of contemporary subjectivities.

Of course, such practices are continually open to neoliberal capture: the privatization of the health-care system, for example, makes it difficult to access hormonal drugs; their use is "politically controlled; and their use, considering their potential for transforming sex, is subject to specific restrictions that espouse administrative criteria and channels of distribution comparable to those of narcotic substances" (Preciado 2013: 392–393). Preciado suggests in response that users of illegal drugs and those diagnosed with gender dysphoria (the potential users of sex hormones) "must organize into associations of copyleft drug consumers and force the state-industry-pharmaceutical-drug-trafficking networks to facilitate free access without restrictions to these biocodes of the production of subjectivity" (Preciado 2013: 393). Ultimately, in this vision, drugs would be managed and produced collectively as *chemical prostheses commons* (Preciado 2013: 393–394). Here again, Preciado refers to monsters: such a collective would constitute "a monster-multitude-in-the-making" (Preciado 2013: 394).

Preciado's book provides a fascinating and challenging analysis of contemporary trans, arguing for the de-medicalization and collectivized use of hormones and other drugs to experiment with and shape bio-psychosocial sex/gender. Resisting psychiatric notions of transgender and oppressive protocols of demonstration, Preciado insists both on freedom and on recognition of the parallels between multiple forms of pharmaco-subjectivity formation: taking the Pill and taking testosterone; drinking alcohol and snorting cocaine. But what does this approach mean for trans children and their parents?

Although *Testojunkie* centers on adult life, early in the memoir Preciado describes a Spanish childhood experience of intense sexual desire for girls focused around "a fantastical construction of a worker's cock" (Preciado 2013: 90):

> Until I was twelve, I went to an all-girl Catholic secondary school. A real lesbian paradise. The best of the little ones were for me. Before they'd even had the time to cross the street and meet the boys at the secondary school opposite, they'd already put their tongues in my mouth. They're mine. (Preciado 2013: 91)

Writing with rage about his mother's attempts to curb this behavior, Preciado recounts refusing to dress or behave like a girl and his passionate, defiant claim on masculinity: "I say: I'm a boy, get it?—and I lift my shirt, show her my nipples that dot a still flat chest—and I deserve the same respect my father gets" (Preciado 2013: 93). Here, in looking back to childhood from an adult perspective, Preciado speaks to a more wildly circulating view: that growing up trans is tough; and that children who do not conform to sex/gender norms are punished, controlled, pathologized. Interestingly, Preciado does not suggest a pharmaco (or indeed any) solution here: children are not explicitly in the imagined monstrous-multitudes. Elsewhere the book is powerfully resistant to reproduction, so perhaps children's experiences—as opposed to memories of childhood—are not on Preciado's mind. But could we extrapolate his arguments to thinking about children's use of puberty blockers?

3 The Medicalization of Childhood Trans

The sociological concept of medicalization articulates the ways in which medicine takes hold of bodies, experiences and subjectivities, processing them through discourses of pathologization and health often involving physical interventions (Zola 1972; Illich 1976; Conrad 2007; Clarke et al. 2010). Coined more recently, "pharmaceuticalization" focuses more specifically on the use of pharmaceuticals to address experiences and bodies previously lived outside medical regimes (hyperactivity in children is one key example) (Williams et al. 2008). The literature on medicalization and pharmaceuticalization is fundamentally critical of both processes, arguing that they restrict life experiences and produce additional suffering. Such critiques carry particular weight when dealing with interventions aimed at children, who are figured as more natural or pure and consequently as at greater risk of harm (Wilson 2011; Roberts 2015). Many recent developments in medical discourses of transgender and transsexual childhoods could be figured as medicalization and/or pharmaceuticalization. But does such a figuration either help young people or allow us to develop better understandings of the inter-implication of pharmaceuticals and (sexed) subjectivities? Might Preciado's copyleft approach provide a viable alternative?

Medical interventions to address issues relating to sex/gender are increasingly available to young people and children and are currently the subject of much medical and popular debate. The World Professional Association for Transgender Health's (WPATH) guidelines for treatment of trans children and young people outline three categories of physical interventions: (1) fully reversible interventions (hormone blockers to delay the physical changes of puberty); (2) partially reversible (hormones used to masculinize or feminize the body); and (3) irreversible changes (surgeries). The WPATH recommends moving slowly and sequentially through the stages to give the adolescent and their families time to adapt (WPATH 2012: 19).

An earlier version of these guidelines, published in 2001, suggested that treatments to delay physical pubertal changes be initiated only after an adolescent reaches the early stages of pubertal development (Tanner Stage 2), giving the young person an opportunity to "experience puberty in his/her biologic sex" (WPATH 2001: 10; see also Roberts 2015, 2016). These guidelines are troubled by population-level changes in pubertal timing which indicate that more and more children are entering puberty before the age of nine (Roberts 2015). In the 2012 revisions, it was noted that "some children may arrive at this stage at very young ages (for example, 9 years of age) and that existing studies of these treatments have only included children of 12 and older" (WPATH 2012: 18).

Treatments to delay puberty are variously described in these guidelines as allowing a young person to pass as a member of their desired sex, as providing more time to explore gender identity and nonconformity and as preventing the growth of sexual characteristics that may be difficult or impossible to alter in later transitioning. Masculinizing or feminizing hormones that can be prescribed after age 16 and so, unlike puberty blockers, do not require parental agreement. Due to the permanent nature of the interventions, the guidelines suggest that young people should have reached the age of legal majority before undertaking surgery (WPATH 2012: 21).[3] Similar guidelines were published in 1998 by the Royal College of Psychiatrists in Britain (di Ceghe et al. 1988).

In 2005, the British Society for Paediatric Endocrinology and Diabetes (BSPED) also published guidelines for medical treatment of trans young people but these advised, in contrast, that puberty blockers should not be offered until Tanner Stage 4 or 5 was reached, that is, until pubertal development was completed. These guidelines were criticized by the

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[3] Castañeda (2015: 266) highlights that the SOC guidelines permit chest surgery in female to male (FtM) young people before the age of legal consent, providing it is "after one year of testosterone treatment" and "preferably after ample time of living in the desired gender role" (WPATH 2012: 21).

Gender Identity Research and Education Society, a British charity for trans people, and their supporters, who argued that there was not sufficient evidence to justify this different approach which would, in their view, cause substantial suffering to some young people (www.gires.org.uk/treatment-BSPED.php). Having earlier removed these guidelines from their website, in 2009 the BSPED published a "Position Statement" on the use of GnRH analogues in trans young people; revising this statement in November 2012 (www.bsped.org.uk/clinical/clinical_position.html). This very brief statement states that cases should be assessed on an individual basis and that treatment decisions should be made by a specialist multidisciplinary treatment team. Although vague, this statement seems to indicate a change of position toward a potentially more positive approach to providing puberty-blocking drugs to younger people. The American Endocrine Society's (2009) draft guidelines, written by US and Dutch clinicians, go further, recommending that adolescents who meet clinical criteria "undergo treatment to suppress pubertal development" (Hembree et al. 2009: 90).

In 1998, Cohen-Kettenis and van Goozen, based at the Department of Child and Adolescent Psychiatry of the Utrecht University Hospital, outlined the perceived benefits of early intervention using GnRH, arguing, "Some individuals who have shown a pattern of extreme cross-sex identification from toddlerhood onwards may develop psychiatric disorders, e.g. depression, anorexia or social phobias, as a consequence of their hopelessness. Social and intellectual development may be adversely influenced" (Cohen-Kettenis and van Goozen 1998: 246). Heed is also paid to the physical boons of such treatment, suggesting greater aesthetic success might be achieved when "treatment is started at an age at which secondary sex characteristics have not been fully developed" (Cohen-Kettenis and van Goozen 1998: 246). This intervention is framed as a normalizing device:

> Ross and Need found that postoperative psychopathology was primarily associated with factors that made it difficult for postoperative transsexuals to pass successfully as their new gender or that continued to remind them of their transsexualism. Furthermore, follow-up studies show that unfavorable postoperative outcome seems to be related to a late rather than

> an early start of the sex reassignment surgery (SRS) procedure. (Delemarre-van de Waal and Cohen-Kettenis 2006: 131)

Part of a network of Gender Identity Clinics funded by the NHS, the Gender Identity Development Service at the Tavistock and Portman NHS Foundation Trust, established in 1989, currently has a monopoly on the prescription of hormone blockers to young people diagnosed with gender identity disorder in the UK. In a document entitled "Information for Parents," the Tavistock and Portman clinics outline that they will see patients up to the age of 18 "who are experiencing difficulties in the development of gender identity." More specifically, the information reveals,

> this includes children who are unhappy about their assigned sex and wish to belong to the other one. Some may be boys who wish to be girls and vice versa; others may show a strong preference for playing with toys mostly used by the other sex, for instance, a boy who mostly plays with dolls. Some children feel comfortable only when playing with peers of the other sex, or may cross dress from time to time. (Tavistock and Portman Trust 2015: 3)

The examples offered betray an underlying assumption of binary gender, and related normative behaviors, which perhaps gives credence to the notion that GnRH analogues are employed strategically as a means of producing and enforcing conventional figurations of sex/gender. As Claudia Castañeda (2015) argues, the burgeoning medical discourse around the hormonal elements of trans childhoods feeds a wider cultural desire for gender clarity and developmental "success." Children who have a complex experience of sex/gender—often experiencing social condemnation of their dress and behavior—are, she argues, increasingly processed within a medical system that in trying to alleviate their suffering offers GnRH analogues to sustain a state of sex/gender immaturity (which can function as indeterminacy), albeit only for a limited time. Although this offer may provide much-needed breathing space for young people, their parents and clinicians, its use is part of a longer-term strategy of gender transition in which sex hormones are used to produce recognizable forms of sex/gender that Castañeda (2015: 262) describes as "an emergent medico-technological transgender normativity." Such interventions risk (or promise?) erasing "all traces of transgenderism in the adult population, creating a marginalized class of otherwise gendered (genderqueer, non-operative transgender, non-gendered etc.) children as well as adults, and perhaps even pathologizing those who might refuse medical treatment" (Castañeda 2015: 269; see also Sadjadi 2013).

In the Tavistock and Portman NHS Trust literature, the rationale for offering child-centered treatment is explained in relation to *adult* gender dysphoria:

> Many adults with gender identity problems describe difficulties in childhood. Often they complain of having been very unhappy children and teenagers and that their feelings had not been understood early enough by parents and professionals. As adult gender identity has its roots in infancy, childhood and adolescence, it can be beneficial to provide specialist help to young people and their families at an early stage. (Tavistock and Portman Trust 2015: 2)

If, as the above suggests, the experience of trans adults is used to inform the treatment of trans young people, might medical recognition of multiple genders in adults, which exceed the dimorphic scope of male and female (e.g., non-binary gender, gender-fluid, agender), impact upon the treatment of young people? Might GnRH analogues become less important if a more bespoke hormonal and surgical approach was adopted in adult services?

These questions will likely wait some time to be answered empirically, as research suggests most adult services still operate within a normative gender binary (Action for Trans* Health 2015).[4] This means that some trans, including those with gender desires rendered undeserving or unintelligible by medical guidelines, procure their own pharmaceuticals from websites such as *AllDayChemist* (http://www.alldaychemist.com) and *Freedom Pharmacy* (http://www.freedom-pharmacy.com). Websites dedicated to advising on the circumnavigation of medical gatekeepers in the acquisition of puberty blockers and transitioning hormones are

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[4] See results of an activist-led "non-binary survey," published in February 2015 *Action for Trans* Health*, working in alliance with GIRES (Gender Identity Research and Education Society).

easy to find, and blogs, vlogs and forum posts on sites such as YouTube reveal broadly two categories of off-prescription hormone and hormone-blocker users; those hampered and frustrated by the time taken to receive medically sanctioned assistance and those who have an agenda that falls beyond the remit of (or is oppositional to, as in Preciado's narrative) medical protocols.

While we have been unable to find any empirical research documenting the affirmative medical experiences of young people who do not identify within the gender binary,[5] we wonder if an expression of non-binary identity by a young person would be clinically framed as part of the "uncertainty" to be explored in the time provided by puberty blockers? If so, might the persistence of non-binarism be figured as a prolonged uncertainty that, in turn, indicates patient/service incompatibility, that is, a termination of medical treatment (hormones/surgery)? Feminist theorist Katrina Roen (2011) suggests this is the case, arguing that medical discourses extolling the virtues of GnRH analogues articulate a view of mental health that depends on subjective and outward identification with one sex (thus also affirming heteronormativity). As noted above, Castañeda (2015) puts it somewhat differently, proposing that a desire for gender itself is at play here.

4 Learning from Early Feminism

The relationship between feminist and trans scholarship and activism is notoriously fraught with debates about who can be included within feminist events, and arguments about transphobia continuing to the present time. Emi Koyama's *Transfeminist Manifesto* (2003) is a clear and positive intervention into these debates. In the manifesto, Koyama declares "sex and gender are both social constructed" and encourages

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[5] There is evidence to suggest that this could alter: In 2015 the NHS hosted a *Child and Adolescent Transgender and Non-Binary Workshop* in which an array of stakeholders, from clinicians to patients and their parents, were invited to share their views. While the workshop highlighted the paucity of provision for children and adolescents who don't identify as male or female, categorizing "non-binary treatment and acceptance" as that which "doesn't currently exist," scope for change was indicated by the inclusion of "non-binary services" in the "combined vision of the pathway" (NHS England 2015).

reclamation (from medical, religious and political authorities) of the right to define them: "Transfeminism views any method of assigning sex to be socially and politically constructed, and advocates a social arrangement where one is free to assign her or his own sex (or non-sex, for that matter)."

Interestingly, the *Manifesto* also encourages learning from the women's health movement:

> For many years, trans people have been arguing with each other about whether or not to demand de-pathologization of gender identity disorder, which is currently a pre-requisite for certain medical treatments. It has been a divisive issue because the pathologization of gender identity disorder allows some of us to receive medical interventions, even though it stigmatizes us and negates our agency at the same time. Before the feminist critiques of modern medicine, female bodies are considered "abnormal" by the male-centred standard of the medical establishment, which resulted in the pathologization of such ordinary experiences of women as menstruation, pregnancy and menopause; it was the women's health movement that forced the medical community to accept that they are part of ordinary human experiences.
>
> *Transfeminism* insists that transsexuality is not an illness or a disorder, but as much a part of the wide spectrum of ordinary human experiences as pregnancy. It is thus not contradictory to demand medical treatment for trans people to be made more accessible, while de-pathologizing "gender identity disorder."

Despite this positive statement about accessing medicine, and although this desire to claim trans as part of "ordinary" experience stands at odds with more recent queer theory which celebrates resistance (Preciado 2013) and wildness (Halberstam 2013), the manifesto shares a view with many contemporary trans theorists that medicine is ideological, part of capitalist systems of capturing and controlling bodies, and thus that accessing medicine as it stands is a limited strategy for addressing trans oppression and suffering. As indicated above, these theorists go further than Koyama, however, suggesting that medical technologies should be accessed *outside* conventional medical arrangements and institutions. Highlighting the unequal distributions of power involved in medical systems, for example, Gill-Peterson argues that trans theorists should pursue “forms of autonomy that could wrest [contemporary transgender biopolitics] … away from the valuation of neoliberal capital and into the hands of not only trans-of-color bodies but all bodies” (Gill-Peterson 2014: 414), while Preciado advocates alliances between those experimenting with sex/gender and users of illicit drugs.

When it comes to children, we suggest, these strategies become more complex: as legal minors, children are generally not able to engage in the kinds of adult-centric politics endorsed by Preciado, Halberstam and Gill-Peterson. On the whole, children remain dependent on adults to fund and/or obtain pharmaceuticals. Arguably, children may also find it more difficult to understand and make decisions about the long-term effects of taking hormonal drugs: what are the consequences for future fertility, for example, or cancer risk? As physically and psychologically developing people, children are in many ways living with uncertainty and change: how might their life stage affect their feelings about gender transitioning technologies (see Castañeda 2015)?

Arguing against developmentalist accounts that understand childhood as part of a linear unfolding of an adult self, Castañeda worries that discourses promoting the use of GnRH analogues adhere to a vision of childhood bodies as malleable and controllable by adults. In the WPATH Standards of Care (SOC) Guidelines (2012), she finds, GnRH analogues are figured as a successful intervention that would resolve gender identification issues through facilitating future “invisible transformation”:

> Furthermore, in a thoroughly technologized world, and as treatment moves from adults to young people with their apparent capacity for more invisible transformation, the SOC guidelines, wittingly or not, are themselves an indication of how changing one’s body to fit one’s gendered identification is increasingly becoming an enactment of a normalized developmental transgression. What the guidelines do not address, or only barely so, is that the bodily dys-phoria of gender exceeds attempts to resolve it through medical treatment, precisely because such treatment makes the false promise of full bodily self-possession, and a kind of completeness of self that is unattainable even through developmental interventions and because development is arguably a legitimizing but ultimately disappointing fiction. (Castañeda 2015: 269)

Importantly, Castañeda does not necessarily suggest withholding puberty blockers from young people: she recognizes—as do we—the profound and important desire for freedom, happiness and justice and the need to escape abuse, violence and stigmatization that these drugs are felt by many to recognize (Castañeda 2015: 269). She does, however, wonder whether using these medications to create later "invisible transitions" is the best way to achieve justice for young trans and non-binary people. Quoting Halberstam (2011), Castañeda asks how modes of "queer failure" (non-normativity; gender disruption) might be recognized and celebrated rather than treated.

Sahar Sadjadi (2013), anthropologist and clinician, similarly suggests that while medical professionals are undoubtedly acting with the best of intentions they may be paying too great heed to an unhelpful narrative, which posits puberty as "a natural disaster," from which children with "gender identity disorder" need to be saved. While Sadjadi, like Castañeda, makes it clear that she isn't writing to "argue against the puberty-suppression of children," she attempts to elucidate the role of alarmist stereotypes in fueling fear of a seemingly inevitable life conjecture, punctuated by ridicule, rejection, misery and the possibility of suicide or murder, in persuading people (doctors, psychologists, parents, trans adults) of the fundamental need for treatment (Sadjadi 2013: 258).

Sadjadi implores people to recognize the bravery, resilience, intelligence and creativity of trans children and to question the pathologization of their non-alliance with the "social expectations of their natal sex." Identifying the root of the problem within the child does not allow for careful consideration of the context in which such discomfort has advanced. A negative future without medical intervention is but one future, not *the* future:

> Consent to a medical treatment that is preventive in nature and justified by *future* gains while entailing harms requires clinicians to allow the parents to imagine and explore various possible *futures* for these children, not the single future of suicide and murder. (Sadjadi 2013: 258)

Sadjadi argues that clinicians are often exposed to a particular version of transgenderism ("adults who seek their services, and the narratives patients produce to access those services, and at times the media portrayal of transgender people") which bolsters the imperative to treat children before puberty and forecloses the envisioning of other possible, future trajectories, those who are transgender outside of the medical, for example, "gender non-conformity without full medical transition or any at all" (Sadjadi 2013: 260). As Halberstam writes,

> [M]any bodies are gender strange and it is time to complicate on the one hand the transsexual models that assign gender deviance only to transsexual bodies and gender normativity to all other bodies, and on the other hand the hetero-normative models that see transsexuality as the solution to gender deviance and homosexuality as a pathological perversion. (Halberstam 1998: 154)[6]

Although Preciado's autobiography may provide a viable alternative of the sort Halberstam and Sadjadi call for, it suggests that becoming a gender artisan requires cultural and social capital and forms of social mobility that may be harder to access as a child or young person (although some young trans people's vlogs do document experimentation with puberty blockers and hormones). While parents or guardians may be able to do some of this work on behalf of their children, the ways in which the medical and trans discourses cited above promote gender dimorphism as "health" (a position that is clearly aligned with broader cultural structures of sex/gender) may prove significant obstacles. The psychosocial modes

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[6] A related (but politically antithetical) argument is made by Sheila Jeffreys (2012) who uses the term *transgender* as a transitive verb, emphasizing her belief that 'transgenderism' is "cultural practice," created and imposed, rather than attributable to the internal life of any individual. Jeffreys parallels the prescription of hormone blockers to trans young people to "gender eugenics," likening present-day treatments with the social engineering of Europe and North America in the early part of the twentieth century. In both instances, sexologists, biologists, endocrinologists and psychiatrists have played a pivotal role—and, claims Jeffreys—in both instances, the subject focus has been the same—lesbians and gays. While acknowledging some differences, Jeffreys argues that hormone blockers, followed with cross-sex hormones, render a person sterile—and that this is similar because the impetus for treatment stems from a failure to conform to the norms of society—in this instance, the norms of gender roles. Jeffreys argues that the diagnostic criteria for gender dysphoria are "based upon gender stereotypes" (2012: 386) and uses Family Court transcripts to discuss how these criteria are "applied in practice," concluding that medical interventions and the transgendering of children is deployed as a technique of behavioral management and a correction device for "nonconforming adults and children" (2012: 387).

of "sexing" enacted in the medical, familial and educational practices entwining children have deep, material(izing) roots.

It seems to us, then, that what might help here is a return to the combination of careful critical thinking and collective, resistant experimentation introduced by Ehrenreich and English and other early feminist health activists. Staying with the troubling conundrum of rejecting sexist medicine while wanting treatment means recognizing that felt needs and bodily (in)capacities are produced—at least in part—by the same discourses and practices that promise to address or intervene in them. Trans is a clear case in point, as Hausman pointed out (see also Stryker and Sullivan 2009), but the same could be said of infertility, menopause or drug addiction. This is not to suggest, in distinction to Raymond's views, that we are typically dominated by medicalization and pharmaceuticalization. But perhaps the wish to become artisans is not enough. If, as Preciado (2013: 398) argues, we are all like her, living "under the control of molecular technologies, hormonal straitjackets intended to maintain biopower" within a pharmacopornographic era, then surely multiple forms of politics are required. Hormones, as Gill-Peterson (2014) points out (see also Roberts 2007), flow inside and outside bodies in difficult-to-control ways that have multiple effects on human and nonhuman bodies and sexualities. Copyleft or wild sex/gender practices provide important new channels for such flows—ones that will hopefully open new psychological and physical spaces for trans children and young people—but they should be part of a wider endocrinological biopolitics that concerns all kinds of hormonal medications, environmental toxins and the full range of human and other-than-human bodies (Roberts 2016). Trans people, including theorists and activists, and their supporters, have an important part to play in these politics, as do feminists, environmentalists, health activists and artists.[7]

Contemporary "sexing" involves vastly complex biopsychosocial processes in which ambivalent relations to medicine and to pharmaceuticals are unavoidable (Roberts 2015). As biomedicine and pharmaceuticals increase their "offer" to manipulate and change the materialities of sex/

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[7] See, for example, the British Film Institute–sponsored program Queering Love, Queering Hormones (www.no-w-here.org.uk/index.php?cat=1&subCat=docdetail&&id=451).

gender, we become ever more ensnared in the conundrum identified by Ehrenreich and English. We live, as Preciado brilliantly summarizes, in a "Pharmacopornographic era." Because this involves physical changes that might be figured and experienced as risks or possibilities by different individuals or groups, at different times, those involved (including theorists) must remain open to, and try to address, expressions of need and suffering while also resisting perceived solutions that may cause additional unwanted harm. Articulating this dilemma and continuing to talk about it in non-defensive ways is a key lesson to be learned from the history of feminist health activism. There may also be lessons to learn from more contemporary activism around the medical treatment of atypical gender. Much research in this field argues that adults are too quick to turn to medical intervention to address atypicality, and even that such interventions are largely driven by adults' desires for clarity about a child's sex/gender and future (Roen 2009; Zeiler and Wickström 2009). While the use of puberty blockers arises in a very different context, driven not by the articulation of a perceived biological difference but by recognition of a child's psychosocial suffering, we might similarly want to carefully explore how, where and by whom "the problem" that is trans-puberty-requiring-GnRH-analogues is articulated. How might this articulation reinforce some of the more oppressive or limiting vectors of our times? And how might these be rendered otherwise?

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Part II

Creating Subjectivities for “Patients” in Advertising

5

Prescribing Relational Subjectivities

Ericka Johnson and Cecilia Åsberg

The project that triggered this book was named "Prescriptive Prescriptions. Pharmaceuticals and 'Healthy' Subjectivities." As discussed in Chap. 1, Introduction, our initial task was to map out and explore how pharmaceuticals were prescribing healthy subject positions for the individuals targeted by them. But pharmaceuticals do much more than prescribe healthy personhood. They also prescribe healthy social relationships whose very existence and enactment can be imagined as requiring the consumption of a prescription medication. The two chapters in this part detail how this is done discursively by focusing on commercial images and texts used to market and sell Alzheimer's, prostate and human papillomavirus pharmaceuticals.

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Before working on this chapter, which focuses on Alzheimer's and prostate medications, we previously analyzed the gendered subject positions prescribed by Alzheimer's medication and Viagra advertisements (Åsberg and Lum 2009; Åsberg and Johnson 2016). In the case of Alzheimer's pharmaceuticals, Cecilia Åsberg, in collaboration with her colleague Jennifer Lum, found that many of the advertisements articulated metaphors of nature and femininity, gendering the pharmaceutical solutions to Alzheimer's, which affects more women than men. Yet the same drugs use discourses of independence and community participation to target male Alzheimer's sufferers (Åsberg and Lum 2009).

Likewise, our earlier collaborative work on Viagra advertising in Sweden has detailed the different shades and contours of masculinity that were used to sell a drug which, ostensibly, is produced to address a symptom of "failed" masculinity: erectile dysfunction (Åsberg and Johnson 2016; cf. Mamo and Fishman 2001; Marshall 2006; Tiefer 2006; Vares and Braun 2006). We found that commercial images of Viagra-consuming men in Sweden represented a Swedish Viagra Man who was imagined to be connected to wild, Nordic nature—pictured in the sparsely populated archipelago or against a rugged and chilly natural background. This figure was also raced and given a social class. He was imagined and visually imaged as white skinned, usually with pale hair, and he was concerned with middle-class preoccupations like tax deductions. Thus, the subject position of a Swedish Viagra Man allows for analysis of a subjectivity that was intersected by gender, class, race and nationality.

What our previous work has also hinted at, however, was that there are more than individual subjectivities being constructed by pharmaceutical advertisements. There are also relationships being presented that are shown as dependent upon the consumption of the pharmaceutical (Johnson and Åsberg 2016). It is to this, the relationship building work of pharmaceuticals in advertisements, that the next two chapters will be looking at. In particular, these chapters will discuss how pharmaceuticals are imagined to facilitate relationships for their subjects. Pharmaceutical advertising is prescribing not only healthy subjectivities, but also healthy relationships, inserting the pharmaceutical product into a relational practice as a necessary component of the subjects enrolled to practice their expected relational responsibilities. Through these relationships, the advertisements also enroll additional people into the production of "healthy" pharmaceutical-consuming subjects.

An assumption of this chapter—and this whole volume—is that pharmaceuticals prescribed by physicians and consumed by many of us today also prescribe particular ways of becoming a healthy subject. By targeting ailments and bodily disorders, pharmaceuticals prescribe what the normal, non-disturbed and non-disordered way of life would be within a theoretical framework of medicalization and pharmaceuticalization. Targeting ailments, disorders, symptoms, complaints or even normal physical developments and turning them into diseases to be treated by doctors has long been discussed as a process of medicalization (Illich 1975; Fox 1977; Conrad 2007). Stemming from this concept, but addressing a specific aspect of it, the term "pharmaceuticalization" has more recently been used to describe the way pharmaceuticals are addressing and creating very specific understandings of health and pharmaceuticalized identities (Elliott 2003; Petryna 2006; Williams et al. 2011; Gabe et al. 2015; Johnson et al. 2016). Both of these processes, and their relationship to a neoliberal social system, have also been critiqued through the concept of biomedicalization (Clarke et al. 2010; Rose and Novas 2004). Commercial decisions about what gets imagined as healthy or unhealthy are both suggestive and colorful in the domain of pharmaceutical advertisements (see Åsberg and Johnson 2016; Johnson and Åsberg 2016). Other research on this topic, in particular from the fields of cultural studies and medical sociology, has shown a rich and varied imaginary, both in online and print texts, and one that prescribes and proposes a personhood ideal that is steeped in an Anglo-Saxon-dominated framework of diversity (rather than difference) (Epstein 2007), self-health regimes (Rose and Novas 2004) and successful aging (Marshall 2006; Katz and Calasanti 2015).

In this chapter, we are looking at two pharmaceutical products which address bodily concerns around aging and loss of physical and cognitive functions. While the medicalization of aging has been discussed in detail, our work is more concerned with the pharmaceuticalization of aging, especially the aspect of pharmaceuticalization in which new social–technical identities are enabled by drugs, and relationships between these subject positions are dependent upon them (cf. Williams et al. 2011; Johnson et al. 2016).

The prostate and its pathologies have attracted a great deal of attention, as has Alzheimer's disease, both in the cultural imaginary and in terms of research funding and drug development. Generally speaking, these two inflictions of aging subjects trigger cultural fears about lost sexuality and gendered identities, and Alzheimer's in particular awakens fears about losing one's personhood or of becoming a burden to relatives or caregivers. These fears are well represented in the pharmaceutical advertising of products to address them.

In her famous work on *Illness as Metaphor,* Susan Sontag describes how diseases and especially disorders associated with old age and, in particular, Alzheimer's disease are crucial matters of concern for all of us:

> Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag 1978: 3)

Her description of the night-side of life, the onerous citizenship, resonates with the fears that underlie much pharmaceutical advertising. But her metaphor of the citizen is particularly relevant to this chapter, as citizenship implies a community of other subjects, others with whom the individual engages in relational practices. While we have found it useful to examine the details of the individual subjectivities presented in pharmaceutical advertisements, we also find it important to consider the affective relationalities to which these subjectivities are ascribed.

1 Methods, Materials

The three advertisements we are analyzing here are aimed at people trying to maintain and enact healthy social interactions, when healthy is understood in very culturally specific ways.

The first advertisement is a picture of an older heterosexual couple, standing close to each other and leaning inward in an intimate manner while looking out at the audience. In typical film poster style, the word "Dignity" is written in blue letters above their heads. Splashed across the poster in yellow and red are the words "extended run" and the brand name of the Alzheimer's drug that alleges to extend cognitive functions.

The second advertisement we consider is for a drug to reduce the symptoms of benign prostatic hyperplasia (BPH), a disease affecting older men that can cause frequent and pressing urination urges (see Chap. 3 for details of diagnosis and treatment). In this advertisement, an older man is driving a blue, convertible car through a rural landscape. The top of the car is down and a woman is in the passenger seat next to him. Attached to the back of the car is a trailer, onto which is strapped a port-a-potty. At the same time, he is waving to a man driving in the opposite direction, also with a port-a-potty strapped to a trailer behind that car.

The third image we will discuss in this chapter is again for an Alzheimer's drug. It shows a grandmother reading a story to a little girl, accompanied by the text, "You see it as maintaining cognitive function. She sees it as a bedtime story."

The prostate drug advertisement was taken from an internet advert for a generic pharmaceutical treatment for BPH. The two Alzheimer's advertisements were found in mainstream medical journals spanning the years 1998–2004.

We are analyzing these images for the relational ties being done in their visuals and the affective responsibilities they imply toward others by the imagined subjectivities on display. To do this, we will be employing close readings of the images and textual composition of the advertisements. We have selected these particular images because they present subject positions which can be connected to categories of people and identities marked by age, gender, race, sexuality and, to some degree, class, and these subjectivities are then presented in relationship with each other and with missing others in the image and text of the advertisements.

2 Theoretical Inspirations

For our analysis, we draw on feminist work on discourses at the intersection of scientific, medical and public spheres, discourses which are involved in the production and reiteration of the body and the self (Bleier 1984; Haraway 1991; Keller 1992; Oudshoorn 1994). This is particularly relevant in the medical context, given the power medical experts and expertise can exert on individuals, a topic of much previous feminist research (cf. Boston Women's Health Book Collective 1971; Petchesky 1986; Davis 1997; Klinge 1997; Meinert 2001). As we have discussed elsewhere (see Åsberg and Johnson 2009; Åsberg and Lum 2009), feminist concerns have ranged from critiquing *biological determinism*, which is perhaps most pointedly encapsulated within the notion that "anatomy is destiny," as Freud in/famously claimed with regard to the female psyche, to problematizing *scientism*, the assumed authority of science in society and the male gendering of scientific expertise (Harding 1986; Traweek 1992). Inspired by this, we place our work within feminist technoscience studies, while using analytical approaches to images from visual culture studies. This allows us to engage with images and narratives circulating around disease, aging, medicine and embodied subjectivity while also considering the material-discursive entanglement with the pharmaceutical.

So, with this approach, we are able to see the pharmaceutical products as ontologically unstable actants that enable the relationships described. Here we draw particular inspiration from discussions about actants and *collectifs* (Callon and Law 1995; Latour 1999), multiple ontologies and bodies (Mol 2002), agential realism (Barad 2007). And while we are not engaging directly with each of these theories in this chapter, their influence on our way of considering the intra-actions between bodies, pharmaceuticals and material-discursive entanglements is fundamental to our approach, not least because it gives us access to the feminist technoscience scholarship which voices a critique of the discursive and material processes through which "non-medical" phenomena become "medical" ones, acquiring the visibility, legibility and urgency of diagnosable conditions through commitment to the notion of "(bio)medicalization" (cf. Clarke et al. 2010). And, of course, we are inspired by

Haraway's foundational exploration of the culturally constituted physical body, which is not a wholly social constructivist body, either, as it recognizes bodily, material agencies that are not necessarily predetermined by "cultural" or "social" constraints. Following Haraway, we articulate the discursive devices through which the medical image of the diseased body becomes a decontextualized, fixed and objective "thing" that is "autotelic and self-referential" (Haraway 1997: 134, 142). This biological fetishism, as applied to for instance "the prostate" and "the brain," works not just to compartmentalize but also to define bodily markers such as "sex," "caring," and the "bodily phases of aging" as "natural referents for the formation of identities, subjectivities, and desires" (cf. Lykke 2002), and naturalizes and legitimizes physical, psychic and social inequalities along the differential axes of sex, age and class in these three advertisements, producing subject positions and their appropriate relationships and the responsibilities rendered available to them in our material.

We show the politics of these material-discursive practices in our analysis more closely than a potentially more neutral study of medicalization or pharmaceuticalization would have done. Medicalization studies have clearly articulated the processes of medicalization, processes which have seen dramatic increases in medical diagnoses during the twentieth century, particularly in diseases like depression, attention deficit hyperactivity disorder, impotence, premature ejaculation, hair loss and weight gain (see Illich 1975; Conrad 2007). Medicalization has been particularly critiqued by feminists, given the attention paid to women's "pathologies" and the resulting medical interventions (Boston Women's Health Book Collective 1971; Ehrenreich and English 1978). The aging body is also a relevant category in the study of medicalization, as the management of men's and women's aging bodies is exemplified by, for instance, hormone replacement therapy (both estrogen and testosterone) as a means to alleviate symptoms of aging and possibly even to prevent the onset of Alzheimer's disease (Klinge 1997; Lum 2006; Roberts 2015) and sildenafil to address "erectile dysfunction" and "female sexual dysfunction" (Marshall 2006; Tiefer 2006; Cacchioni 2015). These pharmaceutical solutions are addressed in studies of pharmaceuticalization (Williams et al. 2011), and we add a theoretical concern for gender and age to the study, using tools from science and technology studies and feminist technoscience to examine issues of social justice and identity in these processes (cf. Applbaum 2006; Biehl 2006; Cacchioni 2015), particularly as we focus on the relationships made possible by pharmaceuticalization.

In line with trends in visual/cultural studies in Northern Europe, we conceptualize "culture" as constituted through the meaning-making practices within the fabric of everyday life and popular media (cf. Franklin et al. 1991; Storey 1993; Lykke 2002). This allows us to read the advertisements for the ways they signify and configure age, gender, class and relationships in relation to embodied modes of being, and especially to categories such as "health" and "disease." We also draw inspiration from various methods of engagement with "figurations" (Braidotti 1994; Bryld and Lykke 2000) and global icons (Franklin et al. 2000), seeing these as assemblages but which are not necessarily stationary. They can travel, and they are sometimes affective and embodied (Ahmed 2004). As feminist technoscience studies do in approaching technology and medicine, feminist studies of visual culture also interrogate the interplay of gender, sexuality, race, nationality and class as expressed within the visual field. Combining these, we consider these intersecting axes of signification as being constituted and sustained through power relations, reinforcing the centrality of historically privileged subject positions marked by masculinity, whiteness and/or Christianity, and marginalizing all others. We draw from feminist visual studies of science and visual scholars such as historian Barbara Maria Stafford (1991, 1996) and Jose van Dijck (1998), who discuss how images and processes of visualization play a highly significant role in both the historical and contemporary practices of technoscience. Feminist visual criticism gives us theoretical insights with a vision of social change, again allowing a political element to our discussion that can highlight the way the cultural imaginary around certain fetishized phenomena, such as the medicalized brain of Alzheimer's disease or the aging prostate, can be conscripted as rhetorical tools in the production of public meaning (cf. Dijck 1998: 197) and the commercial advertising of products to sell them. Seeing pharmaceutical imagery as politics by other means, we can then ask what politics are being done, what (interpersonal power) relations are being (re)constituted in the imagery of the advertisements (see also Åsberg and Lum 2009).

2.1 Coupling Care

The first image we will discuss, taken from an advertisement for an Alzheimer's treatment, is that of the older couple standing close to each other in a stereotypical romantic film poster pose, looking out at the viewer, with the words "Dignity" and "Extended Run" immediately catching the viewer's eye. As Åsberg and Lum have described elsewhere (Åsberg and Lum 2009), there are very particular subjects produced by this advertisement. They appear to be a heterosexual pair, presumably life partners. They also appear to be white, middle class, and well past retirement age, with clothes, jewelry and hairstyles that would have been appropriate for white-collar jobs. Of note for our analysis here is that the two subjects in the image, both the man and the woman, are inscribed with responsibility, toward each other and toward a practice (of drug taking) that will ensure their transition into old age in a dignified way that prevents their becoming burdensome to each other and others. There is an almost moralizing undertone to the image, one which encourages the viewer to maintain health and independence as they age. This encouragement directed to the individual viewer somewhat obscures the complex *collectif* of actors (scientific researchers, medical clinicians, pharmaceutical company executives, legislators, paid caregivers and immediate family members) who are enrolled to shape the contours of collective understandings of Alzheimer's disease.

At the same time, we can see that the concept of mutual responsibility for each other's physical and emotional health is displayed in the classical, heterosexual dyad of the image, and is also implied in the text, "An everyday story of an Alzheimer's sufferer and their carer." This care and responsibility is not assigned to one or the other of the genders, but is constructed as a constituting element of the couple; both care for each other. In the image it is difficult to discern which member of the couple is suffering from dementia and which the carer. This is accentuated by the "film poster" discourse on the advertisement, which says that the "film" is a story about "an Alzheimer's sufferer and their carer."

The ambiguity of this carer/cared-for relationship can be read as downplaying traditional gender roles and sexual difference later in life (even though the overwhelming proportion of carers for elderly loved ones in most western/northern societies, to which this advertisement is directed, are women), but it can also, and more importantly for the commercial advertisement of a pharmaceutical, be seen as positioning the drug as a method of eliminating any pronounced and conspicuous differences between the "normal," "rational" aging subject and the "deviant," "demented" one.

Care, and in particular, physical and emotional care of aging relatives, is a topic of much feminist research (Tronto 1993; Puig de la Bellacasa 2011; Viseu et al. 2015). In this image, however, there is another message we would like to focus on: that both the carer and the cared-for suffer from Alzheimer's in that both of their lives (and the lives of others around them) are deeply affected by the disease. What this mutual suffering does (apart from mirroring what is probably a poignant truth from most people touched by Alzheimer's) is create a relationship which can be connected to and affected by the pharmaceutical. The relationality of the disease—its ability to change our individual and shared lives and relationships—is drawn upon to produce a fertile node into which a pharmaceutical can be inserted. The relationship between the couple is facilitated, is made possible, by the drug. Thus, claims the subtext of the advertisement, the pharmaceutical can be enrolled to extend the run of the "normal" relationship that the couple has (allegedly) enjoyed prior to the threat of Alzheimer's. The pharmaceutical becomes an essential actant in the aging, heterosexual couple's relationship.

2.2 Decoupling That Trailer

In the second advertisement, which is for a pharmaceutical treatment for BPH, the viewer is presented with the image of a silver-haired, white man driving a blue convertible, top down, on a country road. The landscape looks like the American Midwest. The blue sky stretches above green and fertile fields, and farm buildings are in the background. Next to the man is a blonde-haired woman in the passenger seat, smiling. But behind the car, being pulled on a trailer is a port-a-potty. As he is driving the car (and towing the port-a-potty) the man is also waving to another driver (also an older, white man) of a car going in the opposite direction. That car, too, is transporting a port-a-potty.

BPH is a condition in which the prostate becomes enlarged, but it is non-cancerous. According to current medical discourse, this is a normal condition which affects the majority of aging men, though with differing degrees of symptoms. While not directly life threatening, the enlarged prostate can cause urination problems for men, as it can squeeze the urethra or push into the bladder. Men can experience this both as a frequent urge to urinate and with difficulties in emptying their bladder when they are trying to. Many men who are diagnosed with BPH report frustration and difficulty with activities like golf or bus rides, when they may not be able to immediately access a toilet when the urge presents itself. Because of this, and as mentioned briefly in Chap. 3, the commercial advertisements for pharmaceutical treatments for BPH frequently present images that show men doing activities that take time and do not easily allow for frequent urination, like playing golf or chess, or white-water rafting. These images align well with the results of a famous longitudinal prostate study of Midwestern men in the USA, which became a sort of gold standard for the medical knowledge production on BPH and urinary symptoms (Jacobsen et al. 1999). (The cultural specificity of this study and knowledge tends to be ignored.) It is to this understanding of BPH that the image of the port-a-potty pulled behind the convertible is playing, as long car trips are also one of the things that become difficult as BPH develops into a bothersome stage. Many men will find that they become aware of public toilet locations and there are now apps on the market for smartphones that let men search for clean public toilets in larger cities. But a long car trip through a rural area signifies the fear of needing to urinate without being able to do so.

A first line of treatment in many western/northern countries today is the use of alpha-blockers to relax the smooth muscle tissue of the prostate to make it easier to urinate and reduce the need to pee frequently. Instead of having to transport one's own port-a-potty (metaphorically), one can take a daily drug (literally). In the advertisement described here, the pharmaceutical is being positioned as a replacement for the trailer.

As with the Alzheimer's advert described above, in this one the heterosexual couple plays a prominent role in the visual construction of the subjects affected by the disease, and thus the couple are also enrolled in the pharmaceutical solution. The driver in this image is a white-haired man. Sitting next to him is a compliant, smiling, blonde companion, completing the heterosexual dyad. The blue convertible car gives a hint to financial independence, as does the idea of a road trip or even a daytime pleasure ride. The couple in the car is not at work, slaving in an office. They are enjoying their leisure (and possibly post-retirement) time outside, in the sunshine. The woman also is shown as slowed down by and participating in a peripheral way in pulling the trailer, a nod to the discourse that many women are bothered by their partner's frequent urinations, especially at night, and that many complain that their sleep is affected negatively by his frequent trips to the bathroom.

But the most obvious companion is the portable toilet both are pulling on trailers behind the vehicles. One could almost imagine the port-a-potty as a third, unwelcome participant in the relationship, which pharmaceutical ingestion lets the couple get rid of. They can decouple the trailer and drive off into the unknown, without worrying about bathroom trips. At the same time, they can redevelop the intimacy of the original sexual binary and the freedom of a road trip. This plays well to the discourse surrounding prostate issues, which tends to dance around issues of masculinity and sexuality, and the fear of losing both as one ages. The drugs, in this advertisement, facilitate the freedom of a relationship-based adventure.

There is also another human–human relationship in this ad: the homosocial wave between two men on the same road, pulling the same load—their respective port-a-potties. It, too, is formed around the port-a-potty, which is a visual stand-in for the condition of BPH. This other relationship presents BPH as a shared concern by older men, which is in line with the medical discourse that most men will be afflicted by BPH as they get older. Prostate worry becomes a shared concern for men past a certain age. So, rather than participating in male bonding over cars, girls or guns, it is now done over recognition of their shared prostate complaints and, visually in the advertisement, port-a-potty trailers.

The pharmaceutical is positioned as capable of cutting loose the trailer, allowing the man to drive off in his convertible without pulling his own toilet. As such, the drug becomes a facilitator of masculine activities (sporty cars, trucks) and the relationships men may want to have (with women in the passenger seats, other men they meet on the road) without the practical problems associated with BPH. And, in contrast to the first Alzheimer's advertisement, which enrolled the drug to extend the current state of a relationship, in this advertisement, the pharmaceutical is enrolled to return existing practices and relationships to prior normality, one that did not require the port-a-potty on a trailer.

2.3 Bedtime Stories

In the final advertisement we will discuss here, another, intergenerational relationship is facilitated by the pharmaceutical, and Alzheimer's medication enters into relationships of the extended family. This advertisement shows a photograph of a well-groomed, elderly Caucasian woman wearing makeup and glasses, presumably a grandmother, reading a book of fairy tales to her granddaughter. The text for the picture states, "You see it as maintaining cognitive function … She sees it as a bedtime story."

This advertisement presents a very specific subject position for the Alzheimer's situation, and one which is rhetorically mobilized through the use of once-a-day tablets. While these pills can be for both men and women, in this advertisement they are presented with the grandmotherly figure, and used to secure the woman's position within white, middle-class familial life, through the stabilization of her rationality and cognitive functionality. As discussed elsewhere:

> [T]he image in this picture is composed of a warm interaction between an alert and intelligent looking older woman, presumably a grandmother, and her curly-blond grandchild. Her well-maintained appearance, with fashionable yet comfortable clothes, eye glasses and even a golden wedding ring, in conjunction with the loving act of reading a fairy tale to her grandchild, articulates the social relations of a rather well-off, middleclass, ageing woman. (Åsberg and Lum 2009: 109)

Key to our argument here, however, is the "relations" in her social relations. The pharmaceutical is not producing a stable, isolated subject position, but rather one which is being done in relation to the young girl. The girl is gaining from her grandmother's love, warmth and, importantly, clarity. Because the older woman is maintaining her rational subject position through the daily use of the drug, the young girl is able to have her bedtime stories read to her by her grandmother. The drug allows and facilitates the doing of accepted and desired social relations.

This intergenerational relationship is the most visible one in the advertisement, and assumes that the "you" addressed by the text is the grandmother, in a clear case of addressing the individual and encouraging self-management of specific diseases and aging in general. But there is also another possible reading. While not visually present, the "you" could be addressing the sandwich generation, the adult who is responsible for both young children and aging parents, and who may already be enrolled in helping the older generation make medical decisions. Yet, in the imagined ideal of the advertisement, the pharmaceutical not only relieves the adult child of caring for a parent with Alzheimer's, it also allows that parent to care for the adult child's child. As Åsberg and Lum note, having a self-determined and clear-minded grandmother bodes well for the young girl in the image, and her parents. The drug allows the grandmother to do care, even across generations. She is showing responsibility to her granddaughter and, presumably, also to her child, as she assumes caring practices and relieves the adult child temporarily from the bedtime story reading. Thus this advertisement enrolls not only the grandmother and the grandchild in the relationship but also by default even the adult child (Åsberg and Lum 2009: 109f).

Thus the pharmaceutical becomes discursively necessary for the production and enactment of social relationships across three generations.

3 Conclusion: Pharma-Mediated Relationship Practices

In the three commercial examples of advertisements discussed, a pharmaceutical product is discursively positioned as an essential element in the production, reproduction and practice of (normal, healthy) intimate relationships. In the first example, a drug that claims to delay the onset or progression of Alzheimer's disease is presented as a way to extend the lifespan of an otherwise threatened heterosexual dyad. The caring couple can continue to care for each other and grow old together with dignity, rather than losing their relationship to the confusion of disease. In the second example, a pharmaceutical product to treat the symptoms of BPH is positioned as a way of reducing the negative effects of the consequence for both the man and the woman in a heterosexual relationship. Rather than having to pull a portable toilet around with them, the couple is able to drive off in their convertible, unhindered by urination worries. And in the final example, a drug is presented as an essential actant which can allow a grandmother to continue her caring role for her grandchildren, creating the ability to do caring intergenerational relationships. The aging body, the drug advertisements seem to suggest, can be managed, as can the culturally prescribed binary gender norms be maintained well into old age. Masculinity and its prescribed bounded and non-leaky body need not be associated with serial bathroom breaks, and femininity as associated with relationship care can be upheld through the proposed social powers of the pharmaceuticals.

Our analysis has first explored these ads for the self-caring subjectivities that are conceived as a contingent, emergent product of an apparatus of bodily production, sustained by the co-constitutive interplay between medical discourse and bodily matter. These subjectivities are interesting in and of themselves, not least for the intersectional elements of identity they display and reproduce, as our other work has detailed (Åsberg and Lum 2009; Johnson et al. 2016). However, of particular interest here is the way that these subject positions are not created in isolation. The pharmaceutical marketing techniques and visual and rhetorical conventions also create relationships for the subjectivities, ones which are dependent upon the consumption of the drug, essentially saying, “Do you want to enjoy time with your partner/drive off with a beautiful lady/read stories to your grandchild? Then take our drug.” The drug is part of the relational agency in which the subjects engage, which allows a person to participate in their social relationships, to perform relational work, including closeness, love, intimacy, caring and responsibility.

Prescriptive prescriptions are not only prescribing for an individual’s body or mind and subjectivity; they are also prescribing relationships, interactions and emotions and affects. The drugs facilitate relationships (the decoupling of the port-a-potty, freedom to drive off with a woman in the passenger seat). They enable the performance of relationships, with the caring for the partner in the dignity ad, and they allow relationships to continue (the caring for the grandchild). The pharmaceuticals are prescribing both the subject positions and the relational social interactions between the imagined pharmaceutical subjectivities and the (gendered, classed and generational) roles the individuals play in those relationships. This also constructs the disease and its solution as a concern of a wider group of potential customers. Significantly, creating a constellation of interested parties through relationships also allows for a wider target audience for the advertisement, as will be explored in more detail in Chap. 6.

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6

You Will Protect Your Daughter, Right?

Lisa Lindén

This chapter explores how direct-to-consumer (DTC) advertising in Sweden for the human papillomavirus (HPV) vaccine Gardasil (advertised as a vaccine for young girls for the prevention of cervical cancer)[1] addresses parents and articulates gendered parental care relationships. Vaccination practice invokes a tension between the collective good and individual choice, and encourages parents to exercise good consumer choices for their children (Rose and Blume 2003; Fairhead and Leach 2007). The trope of parents-as-consumers can present the management of health risks as an individual responsibility rather than a matter of population health (Reich 2014). Vaccination practices can be read as an

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[1] Gardasil is used to prevent two strains of HPV which are estimated to cause 70% of cervical cancer cases per year, as well as two strains that are estimated to cause 90% of genital wart cases per year. More than 100 different types of HPV exist, whereof 14 types can cause cervical cancer, cytological abnormalities and precancerous lesions. HPV is transmitted through genital skin-to-skin contact. Both men and women transmit HPV (Medical Products Agency 2015b).

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example of a pharmaceuticalization of life, which transforms the relations between, in this case, parents, daughters, health professionals and pharmaceutical companies, and creates new relations of caring which require the involvement of pharmaceuticals as essential participants (even when actively resisted by potential recipients) in the relationship (cf. Williams et al. 2009, 2011).

Since 2012, Gardasil has been part of the Swedish vaccination program and, as such, is offered free of charge to girls born in 1999 or later, but not to boys (Medical Products Agency 2015b).[2] At this point, Gardasil and all other vaccines included in the Swedish vaccination program are free to all children in Sweden and distributed through the tax-funded health-care and school systems. Parents have the option to opt out of any or all vaccines with no formal repercussions, though this is not common. However, between 2008 and 2010, the period before the decision to include Gardasil in the vaccination program was taken, there was extensive DTC advertising for the vaccine, advertising which partly addressed the parents of girls aged 13–17,[3] and partly this group of girls themselves.

Sweden is the only EU country that allows for direct marketing for vaccines against infectious diseases in humans *without* prior approval by competent authorities of the member states. Swedish legislation for marketing of pharmaceuticals states that it is forbidden to directly market prescription pharmaceuticals to the general public, with "the exception of campaigns for vaccinations of humans against infectious diseases"[4] (Medical Products Agency 2015a). In contrast, the current EU directive states, "the prohibition [of DTC marketing of prescription pharmaceuticals] shall not apply to vaccination campaigns carried out by the industry and approved by the competent authorities of the Member States" (EU Directive 2004/27/EC 2004). Hence, in the EU, DTC advertising is

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[2] In 2013 Australia decided to implement a vaccination scheme for both boys and girls, and in 2014, Austria did the same. For a discussion of the gender-neutral discourse currently articulated in Austria, see Lindén and Busse (Chap. 9, this volume).

[3] At this time, subsidized pharmaceuticals in Sweden meant that the patient did not have to pay more than 1800 Swedish kronor (SEK) (US$218) for prescription pharmaceuticals within a calendar year. Since January 2012, the maximum sum is 2200 SEK (US$266) (Dental and Pharmaceutical Benefits Agency 2015).

[4] All translations are the author's.

allowed for vaccines if the campaigns are approved before being launched to the general public.

The Swedish decision to allow for DTC campaigns without prior approval was due to Sweden's strong Freedom of the Press Act[5] and general freedom of speech legislation, which includes a prohibition against state preview of the content of printed material in radio and TV programs (Medical Products Agency 2008). In the Swedish bill it was stated that:

> if an authority needed prior access to vaccination campaigns [for approval purposes], this would go counter to the censorship prohibition in the Freedom of the Press Act and freedom of speech legislation. Against this backdrop, no such rules should be introduced. (Swedish Government 2005: 204–205)

In relation to the HPV vaccine, this legislation was debated by medical professionals and authorities, politicians and journalists. It was, for instance, argued that it was a misinterpretation of the law to let pharmaceutical companies advertise directly to citizens (Engström 2008; Hedlund 2008), that it was problematic because it implies a commercialization of public health (Linnersten 2008) and that a reduction of medical complexity evident in the advertising could be seen as an "enormous betrayal of Swedish women" (Rehnqvist et al. 2008).

Apart from the Swedish case which allows advertisements for vaccinations, DTC for prescription pharmaceuticals is allowed only in the United States and in New Zealand. Therefore, for the purposes of this chapter, studies of the US case will be examined as useful points in contrast to my Swedish material. The DTC advertising for the HPV vaccine in the United States has constructed girls and parents as individually responsible vaccine consumers. An often-discussed case is the Merck campaign "One Less," in which girls were depicted as empowered individuals who choose to get vaccinated as a way of handling individualized risk for cervical cancer in the future (Mamo et al. 2010; Vardeman-Winter 2012). This advertising was focused on cancer instead of sexuality due to a pre-

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[5] 1766 (http://www.government.se/articles/2016/06/the-swedish-press-act-250-years-of-freedom-of-the-press/).

vious US debate articulating the vaccine as enabling female promiscuity (Casper and Carpenter 2008). As I will show, the Swedish DTC ads differ from the US ones in how gendered parental care responsibility is depicted and articulated. In addition, North American readers may be interested in knowing that there has been no discussion of unwanted sexual promiscuity associated with the introduction of the HPV vaccine in Sweden, perhaps reflecting a general acceptance of teenage sexuality. In the public debate, Gardasil is therefore not treated as qualitatively different from other vaccines in Sweden (Lindén 2016).

The US "One Less" campaign represented mothers as being responsible for the health of their daughters by positing them as experienced and wise experts regarding their daughters' (sexual) health (Mamo et al. 2010: 137–138). It has been shown how DTC ads often portray women as caring for, and being responsible for, others' bodies and health. Beyond studies on DTC ads for the HPV vaccine, Viagra DTC ads also serve as a good contextualizing example here. Female partners in ads for Viagra are constructed as responsible for emotionally supporting their male partners' sexual activities and Viagra consumption (Mamo and Fishman 2001; Johnson and Åsberg 2012). In this chapter, I will show how Gardasil DTC ads depict the vaccine as a product with which parents, and especially mothers, can do care responsibly. This, I assert, creates a space for care relationships which involve pharmaceuticals.

In addition to the specificities regarding DTC advertising, Sweden also differs from countries such as the United States regarding healthcare discourses and practices. In Sweden, state-funded management of public health has functioned as a central strand in discourses about welfare, nationality and citizenship. In this way, "the Nordic welfare state is a regime that can broadly be characterized by universalism and state responsibility for a large part of care (preschool, the elderly, the sick, and the challenged) through regulation, funding and (originally) the provision of care" (Dahl 2012: 284). Responsibility for care has been understood first and foremost as a public and collective responsibility within a citizen–state relationship rather than as an individual one. Governance of the parent–child relationship through children's health and quality of life has been an important area for public health interventions (see Forsberg 2009). Nationwide, state-funded vaccinations (see Sköld 1996;

Bragesjö and Hallberg 2009); child and adolescent care interventions (see Ohrlander 1992; Bergman et al. 2011) and sexual health interventions for children (see Bergenheim 1994) are all examples of public policies directed at the health of children and the actions of parents.

More recently, Swedish health care has been transformed due to the marketization of the health-care sector, which places responsibility for health on individual citizens. It has been argued that when neo-liberalism meets the Nordic welfare state, "care as relational becomes an antiquated notion, and instead neo-liberalism forces us to see new forms of care" (Dahl 2012: 285). In contrast, drawing on feminist science and technology studies (STS) work on care that includes nonhumans as important actors, I argue that care in the Nordic context can still be understood as relational even though it is individualized.

It is often stated that in western countries parenting today needs to be understood as a discourse and practice that positions parents as risk managers with individual responsibility for handling how their children are exposed to different risks (Forsberg 2009). As is apparent in the Swedish Gardasil ads, this parenting discourse often constitutes the mother as the primary caregiver through a discourse on "intensive mothering," positioning mothering as child centered rather than as domestically focused (Wall and Arnold 2007; Miller 2011) and including expert guidance as a crucial component for how individual, yet gendered, care responsibility is constructed (Lee et al. 2010). Hence, parenting is a highly gendered discourse that tends to give mothers responsibility for being an informed parent *and* for emotional accessibility, assumedly to guarantee the child's future well-being (Elvin-Nowak and Thomsson 2001).

Fathering, in turn, is often discussed through an "involved fathers" discourse that constructs gendered, caring masculinities in relation to new, gender-equality ideals (Bergman and Hobson 2002; Johansson and Klinth 2007). It has been shown that male caring identities are constructed as associated with doing care work in outdoor activities and sports with their children (Brandth and Kvande 1998; Doucet 2006). Moreover, fathers are often positioned as responsible for fostering children to become independent future citizens (Johansson and Klinth 2007). Interestingly, the DTC ads for Gardasil differ from this, as fathers are *not* portrayed through caring masculinities or as fostering independence.

Both classical theorists in feminist ethics of care (Tronto 1993; Sevenhuijsen 1998) and later feminist STS scholars who have involved materiality in caring (Mol 2008; Puig de la Bellacasa 2012) highlight that a focus on care generates an opportunity to challenge a predominant focus on individual responsibility. Focusing on how individual responsibility is done through caring relations makes it possible to challenge the idea that citizens freely make choices in a health-care market. This does not seem so odd in Sweden, with its historically strong, if somewhat tarnished, ideal of solidarity and collective responsibility. In addition, using caring relations as an analytical prism makes it possible for us to be responsive to how Gardasil takes part in these caring relationships as a nonhuman actor (cf. Berg and Mol 1998; Mol 2002). I make use of these insights to show how different articulations of care responsibility are linked to gender, sexuality and nationality. In the ads, mothers are visualized as responsible for their daughters' health, while fathers are often positioned as invisible others in the gender-neutral category of "parents," articulating how care responsibilities are distributed in gendered ways. I discuss the implications of making mothers responsible for care work and making fathers invisible, and contextualize this in relation to the discourses on intensive mothering and involved fathers.

1 Methodology and Materials

For this study, I have sampled advertising produced by the pharmaceutical company Sanofi Pasteur. This material comprises letters, images and educational pamphlets sent to all Swedish households with teenage daughters who were between 13 and 17 years old in 2008, 2009 and 2010. In addition, the advertising material contains print, internet and TV advertisements that appeared in national newspapers, on one of the main TV channels, and on Facebook. This advertising probably reached large parts of the Swedish population. The specific subset of material analyzed for this chapter consists of 17 ads, and is part of a bigger collection of empirical material discussed in Lindén (2013, 2016), which includes both pharmaceutical DTC ads and county council public information campaigns.

The DTC advertisements analyzed here were developed uniquely for the Swedish market by a larger image agency, a task assigned by the Swedish Sanofi Pasteur office. Despite the fact that the ads were developed for the Swedish market, there are some parallels between the Swedish campaign and the US one, such as the fact that both campaigns contain a video showing girls playing basketball (see Lindén 2013). In the Swedish ads, almost everyone is white, in contrast to the US "One less" campaign, which portrays girls and parents through a discourse on multiculturalism (Mamo et al. 2010).

The analytic and methodological framework is derived from the feminist STS scholar Adele Clarke's (2005) situational analysis and her guidelines on how to carry out visual and nonvisual discourse analysis (Clarke 2005). Following the argumentation by Clarke, I coded the material, using analytical memos, sensitizing concepts and an ordered situational map. These methodological tools made it possible to analyze different forms of empirical material as part of the same analysis. In addition, it allowed me to approach nonhumans and humans together by mapping out the discursive relations between these in the situation of inquiry. Clarke's notion of invisible, yet implicated, others was used to discuss how mothers were tasked with the main caring responsibility in the ads in part by making father subjectivities invisible.

1.1 Parents Calculating Cervical Cancer Risk

In the Swedish Gardasil ads, parents are encouraged to consume Gardasil through their daughters' bodies, something which enacts different parent responsibilities and care relationships. An example of this can be found in three DTC letters. These letters include no images, just text, explicitly addressed to the parents (and not mothers or fathers in a gender-specific way) of teenage girls. However, since they were sent to Swedish households together with cards containing visual images of middle-aged women with young girls, these letters, together with the cards, address viewers through imagery of mothering and the mother–daughter relationship.

All three letters, which were very similar to each other, included information that girls aged 13–17 would get the vaccine partially subsidized by the state; details about how the subsidy worked; how to get vaccinated and statistics about how common is cervical cancer. They also mentioned that cervical cancer is caused by HPV, but that it is important to continue Pap smear screening later in life and to use a condom. In addition, the letters included information about how to contact Sanofi Pasteur for more details. In the letter, there was a "good to know" list. This included similar information as in the main text, such as the price for the vaccine with and without subsidy, how to go about getting the vaccine and reassuring statements such as "Gardasil exists in 74 countries and so far over ten million women all over the world have started getting vaccinated with Gardasil" and "it is not too late to get vaccinated, even if [your daughter] has started having sex." In this way, parents are encouraged to get their daughters vaccinated—ten million other women already have done it all over the world—and are told that the vaccination is widely used, safe and good. Additionally, in mentioning sex and condoms, Gardasil is connected to sexual practices. This differs from the United States, where HPV vaccination has often been depicted in DTC ads as distanced from sexuality (Mamo et al. 2010; Lindén 2013).

The letters contained a combination of informality and formality. They greeted parents with a "Hi!" or "Hi, parents of teenagers!," something which can be contrasted with the more formal use of "dear" or "to whom it may concern." Framing the letter in this informal way, through everyday language, allowed Sanofi Pasteur to position themselves as a friend of the parents. But the use of information about the vaccination, the subsidization and statistics on cervical cancer prevalence also conjured up an expert position. This is indicative of the marketing approach of "personal" expert advice related to (children's) health as well as appellations to parental responsibility (Murphy 2003; Knaak 2010) and to how mothers have been discussed in relation to US HPV vaccine ads (Mamo et al. 2010).

One of the letters stated that "cervical cancer is the third most common form of cancer amongst 20–44 year old women in Sweden. Every year approximately 450 women are diagnosed with cervical cancer and 150 of them die. But it is possible to prevent cervical cancer!" In a way similar to Prothero's (2006) discussion of how advertising directed to mothers uses fear to sell products, the statistics connected to death rates in these ads articulate anxiety to make parents comprehend the severity of the risk position their daughter is in as a potential future cervical cancer patient. The letters not only depict the authority of an expert, but also include articulations of risk. By articulating statistics in this way, a cervical cancer diagnosis and death is implicitly contrasted with the amount of money the girls' parents are encouraged to spend on Gardasil. Parents are encouraged to measure the cost of consuming Gardasil against the risks of their daughter developing cervical cancer in the future. It is implicitly suggested that the daughter is at risk if Gardasil is not consumed. Parents need to choose between jeopardizing their daughters' future life or their consuming Gardasil. Invoking fear is envisaged as leading parents to understand that their daughter is at risk and that they therefore need to take action and get her vaccinated, presented as the rational, good parental choice to make. Hence, emotion and rationality are interlinked.

Producing a market for cervical cancer in which parents ought to calculate cervical cancer risk and Gardasil benefits is an example of how the HPV vaccine brings about a pharmaceuticalization of cervical cancer; cervical risk is presented as having a pharmaceutical solution that can be purchased on a health market (cf. Williams et al. 2011). Through the use of statistics about the risk of getting the disease, a future of healthiness is implicitly contrasted with a future including cervical cancer. Consuming Gardasil is presented as the right choice to prevent cervical cancer, and parents as responsible for making that choice, encouraging parents to act upon a future potential threat *now*. Parents are depicted as risk managers anticipating future disease and, therefore, the Gardasil ads invoke an anticipation regime that reconfigures "the possible" into a need for taking action now (cf. Adams et al. 2009). A pharmaceutical product is inserted into the responsible parent–healthy daughter relationship.

As mentioned in Sect. 1.1, in the cards sent in the same envelope as the letters, women are pictured together with girls, and positioned as mothers. Therefore norms on mothering are also indirectly a part of how parents are addressed in the letters. On the front page of one of the cards, a mother and two daughters are shown camping together. In other pictures there are images of girls out biking in the forest, or standing happily and warmly dressed against a green and wild forest backdrop or in conversation with their mother outside and dressed practically and warmly. Text overlays tell the viewer to "Remember Gardasil!" Using this combination of text and image, the cards indicate that mothers are especially suitable for emotional and supportive care of children, and that Gardasil is the way for mothers to be able to do this care work. Mothers, in particular, should remember Gardasil.

One possible reading of these images is that they address *parents* through norms about mothering, care and the child–mother relationship. Within this interpretation, it is possible to argue that norms about mothers as the supportive and emotional caregiver help to encourage all parents—mothers, fathers, guardians—to consume Gardasil; yet the parents who are encouraged to take responsibility for consumption could be both fathers and/or mothers. Another possible reading is that, as only mothers are pictured, the letter is first and foremost discursively addressing *mothers*. Both these readings are possible due to the interpretative flexibility of images (cf. Sturken and Cartwright 2009).

I argue, however, that the visual depiction of mothers as caring for their daughters positions mothers as having an important caring responsibility, and a caring mother subjectivity is enacted in the cards. In this way, the mother is addressed as a caring, good and responsible parent who wants to preserve the future health of her daughter by acting as a risk manager in the present.

2 Parent–Daughter Relations Through Tropes of Nature

In one pamphlet, a girl is pictured against the background of deciduous trees. The girl is dressed in winter clothes; a blue beanie and what looks like a white, winter jacket. She is accompanied by the text "To you who have thought about vaccinating your daughter against cervical cancer but haven't made up your mind, yet." It is followed by information about the vaccine, similar to the information in the previously discussed letters. In this ad, deciduous trees convey a sense of being close to nature. But this image also underlines parental responsibility through the message that Gardasil is the right choice to make: if the parents care for their daughter, they should see to it that she is vaccinated with Gardasil. Since this ad includes no images of possible mothers, it can be interpreted as addressing both mothers and fathers as parents. A sense of being close to nature is here related to the relationship between parents, daughters and Gardasil: they want to be a caring parent who aims at preserving the health of their daughter so that she can keep on living a healthy, outdoor life, and thus they need to consume Gardasil through the daughter's body. This image is similar to another picture where a girl is portrayed biking against the backdrop of a Falun red house,[6] fir and oak trees. In addressing parents, the girl is accompanied by the text "Do you remember that vaccine against cervical cancer is most effective if taken during the teenage years?" A relationship between the traditional nature–culture environments of Sweden and girls, parents and Gardasil is invoked.

In two other ads, a mother is shown camping with her two daughters (one looks like a teenager and the other one a little older). They are photographed in a glade in a pine forest, with a lake in the background. One can discern a picnic table and camping kitchen equipment, but the main focus of the image is the modern, lightweight tent that the girls themselves are putting up. The two daughters are trying to tackle the final steps of setting up a tent, while the mother observes them. Sun rays stream down upon the group. They are all dressed in casual clothing; jeans, T-shirts, sweaters and sneakers. This image is gendered, since the mother and the daughters are visualized through female coded norms related to clothes, hairdos and makeup. In addition it calls to mind a linkage of women with nature, something which is one side of a predominant western dichotomy; women as nature and men as culture. Yet at the same time, the group is out camping, confronting nature—or at least occupying it—without the presence of men. This could be read as a modern, feminist, progressive mothering, creating parallels to the modern, progressive, medical development that Gardasil offers. It invokes a sense of women's independence, spending time in the wild without the presence of men. Mothers are depicted as doing care and fostering independence through joint outdoor activities with their children without the presence of possible fathers, rather than fathers enacting caring mascu-

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[6] Falun red is a typically Swedish color often found in the Swedish countryside.

linities through outdoor activities (cf. Brandth and Kvande 1998; Doucet 2006). Here, the mother is given this role.

This ad invokes "the natural" as a powerful humanist trope which connects Swedish landscapes and natural environments with cultural assumptions of Swedish mothers and daughters. (Gender intersects with "race" and nationality here too; the mother and daughters are all visibly white.) In this image, Gardasil is positioned as a natural element in the mother–daughter relationship against a context of Swedish landscape; a discourse about the landscapes of Sweden is co-constituted with one of a gendered Swedish subjectivity. As Åsberg and Johnson assert in the case of advertising for Viagra in Sweden, ideas of "the natural" are "often working through a cultural imperative of preservation" and it is a "powerful trope through which subject positioning and identity formation works" (Åsberg and Johnson 2009: 11). The imaged landscape in the Gardasil ad helps to create a space for this gendered mother–daughter relationship. The glade invokes a peaceful resting place. In the Swedish cultural heritage, the symbol of the glade can be found in the Nobel Prize–winning poet Tomas Tranströmer's famous poem "The Glade." The glade is also a common name for nursery schools and is used frequently in information and marketing brochures for nature reserves.

Through the image of the mother and her daughters camping in a glade, nature is reinvented and imagined as a restful backdrop, a place for mothers and daughters to go to make sense of their lives, experiences and hopes for the future; the idealized Swedish wilderness makes it possible for the mother and her daughters to have some quality time together. This builds on an idea of mothering as something natural that, by nature, creates a special caring bond between mothers and daughters. However, this relational caring practice is mediated through the presence of Gardasil, which creates an opportunity for the mother and daughter to have some special mother to daughter talk, heightened by the discourse that positions the mother as the one who should talk with the daughter about intimate things related to bodily health and sexuality. Therefore, the image can be interpreted as invoking a situation where the mother can talk with her daughters about HPV, cervical cancer and the importance of Gardasil, relying on an idea of the *natural* mother–daughter relationship in a *natural* Swedish landscape with the *natural* third party, Gardasil.

Picturing mothers and daughters in forests, among trees and in the countryside, with Falun red farmhouses as in another ad, calls to mind symbolism relating to nature, gender and nationality. In the image of the mother and her daughters camping, idealized Swedish nature is intertwined with a Swedish outdoors, close-to-nature, nationality. Hence, norms on nature and nationality are interlinked, and the ad draws on historical discourses articulating mothers as close to nature, the earth and the nation, playing on norms about women as responsible for the health of the nation, its citizens and landscapes. By positioning mothers as caregivers and girls as care takers in images of landscapes often related to idealized Swedish selfhood, ideas of historical population health are also evoked. Mothers have long been seen as responsible not only for the health of the family but also for the health of the nation (Yuval-Davis 1997). In Sweden, the Mother Svea figure has historically embodied this "mother of the nation" discourse that literally reenacts the Swedish nation (Tornbjer 2002; Eduards 2007).

At the same time, since Gardasil needed to be actively purchased by parents when these ads were produced, responsibility for the vaccination is removed from the state. The depiction of the mother and her daughters as related to Swedish nature–culture is, thus, connected to Gardasil as a consumer choice that individual parents should make. Therefore, the discursive figures of the population and the individual are connected through tropes of the nation together with articulations of consumer choice. The combination of consumer choice and symbolism of mothers' responsibility for population health enacts mother and daughter subjectivities related both to the population, the nation and the individual, and to the new product, Gardasil.

2.1 The Pharmaceuticalized Parent–Daughter Relationship

In this chapter, I have discussed Gardasil's participation in parent–daughter relationships as an example of pharmaceuticalization opening new forms of care relationships which include pharmaceuticals as essential partners. I have discussed how parents are depicted as risk managers who are responsible for caring for their daughters through choosing to consume Gardasil. As Reich (2014) has explored, these choices are made in the negotiation space between state policies to protect the herd and personal choice, a space that is largely dependent on an individual's (or family's) socioeconomic status. It is a privilege to be allowed to, and to believe that one has the right to, negotiate within it. And as Reich noted in her US material, I also saw in the Swedish material that the primary actor in this space is the mother.

Commonly, different parental subjectivities coexist; parents are often caregivers, risk managers, calculative consumers, and responsible for their daughters, all at the same time. Mothers are often consumers, risk managers, and caregivers in the same ads. They are viewed as both responsible for emotionally supporting their daughters and, through symbolism related to Swedish mothering, for maintaining the population's health. This means that a contemporary discourse on intensive mothering coexists with an older one relating mothering to care for the population's health. Fathers, in turn, are positioned as invisible others. Sometimes they are addressed as parents and, as a part of that, as consumers. However, fathering as a possible subject position is made invisible in the ads. Parents are *not* addressed through caring or involved father masculinities, as in other prevailing discourses in Nordic countries.

Parents are asked to exercise citizenship through consuming Gardasil. This is still true now, when Gardasil is offered as part of the standard, free vaccination program through the school system, though with the difference that now parents must opt out rather than actively consume the product. This change makes the vaccination more available and accessible to underprivileged and marginalized groups in Sweden, and is an interesting counterpoint to healthism and increased individual responsibility for health (see Reich 2014). In the pre-vaccination program material I have studied here, parents (read: mothers) are positioned as simultaneously active consumers and good citizens, fulfilling a civic responsibility *through* the act of consumption. In this way, HPV vaccination is here turned into a consumer responsibility for parents. As I have shown, this is possible through the mutually dependent processes of pharmaceuticalization of cervical cancer and gendered parental responsibility.

The material I have presented here has some interesting implications for both young women and for the parent–daughter relationship. For young women, Gardasil becomes a pharmaceutical element of their (future) healthy subjectivity. In the commercial material, Gardasil is an essential element of becoming a healthy subject. Accessing vaccination connects them with active, healthy selves and avoids the articulated future threat of (cervical) cancer.

Gardasil also becomes an essential participant in the good, caring parent–daughter relationships presented in the campaign material. Relationships that involved caring responsibilities between parents and daughters existed in Sweden prior to the introduction of Gardasil. Likewise, the association of mothering and nature in Sweden has also existed for quite some time, long prior to the HPV vaccine. These are not new relations as such. What is new is the presence of Gardasil in the material I have analyzed, and Gardasil as a nonhuman actor that re/produces gendered, Swedish relationships. It positions mothers as privileged carers and young women as recipients of the vaccine against a sexually transmitted infection, even as sexual practice is regarded as morally unproblematic. Using a theoretical framework of pharmaceuticalization, I read these ads to show Gardasil as a participant in these relations and allow an analysis of what the product is doing in these new relationship constellations. Pharmaceutical marketing demonstrates this aspect of pharmaceuticalization, in which pharmaceutical products are easily and frequently creating new relationship constellations, inserted into relations where they previously were not present.

Creating new, healthy subjectivities that include the use of a pharmaceutical is not unique to the HPV vaccine, as literature about successful aging and sexuality in particular has shown (Marshall and Katz 2002; Tiefer 2006). Likewise, this practice of relationship building within vaccination practices is not a new development. Many earlier vaccination campaigns have also relied on the image of responsible citizens and parents (see Colgrove 2006; Munro-Prescott 2010). But inserting the vaccine into the parent–daughter relationship is both very lucrative for the pharmaceutical company, and hard to resist, because both parents and daughters must enact resistance.

In this chapter, I have viewed the pharmaceutical product as a non-human participant in relationship-building practices, rather than focusing only on the actions of regulatory and commercial actors, as perhaps would be more easily done within traditional medicalization discourses (see Conrad 2007; Bell and Figert 2012). While the state and commercial actors are, of course, important to consider, I, in an STS spirit, suggest that the new caring relationships involving pharmaceutical products in marketing material are of analytical and political interest, opening up for questions of how technologies, and pharmaceuticals in particular, are active agents in our lives, and which carry with them and enroll consumers into commercial and political *collectifs*.

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Part III

Different HPV Vaccines

7

Evidence, Sex and State Paternalism: Intersecting Global Connections in the Introduction of HPV Vaccines in Colombia

Oscar Javier Maldonado

HPV (human papillomavirus) vaccines provide an opportunity to trace local connections that configure the global circulation of drugs (see Lindén (Chap. 6, this volume); Lindén and Busse (Chap. 9, this volume); Hanbury (Chap. 8, this volume); Johnson et al. 2016). The multiple and almost simultaneous reception of HPV vaccines in different countries shows the local adaptation, translation and enactment of some "global" narratives, policies and market strategies around drugs. In the case of HPV vaccines, narratives around girlhood, women's empowerment, motherhood and parental care have had a global reach through vaccination campaigns, advertisements and public health discourses. The reactions of parents, media and government to these discourses have varied from country to country, some showing similarity, others marked differences. For instance, the involvement of politicians with the HPV vaccination has varied from explicit political debate (e.g., the United States), to political consensus (Mexico, Brazil and Colombia), to silence and no explicit involvement (e.g., the UK and Sweden).

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In Colombia, as in other Latin American countries, journalists and politicians have widely praised HPV vaccines as a public health intervention against cervical cancer since 2009. The launches of the vaccination campaigns have been public events with the presence of the president and health ministers. Such enthusiasm among politicians and health-care authorities has been connected to the burden of cervical cancer in the region and a generalized perception of vaccines as public goods.

Cervical cancer is the second-most frequent cancer in women in the world and the third-most common cause of death from cancer in women. The World Health Organization (WHO) estimates that more than 85 percent of the 270,000 deaths from cervical cancer every year occur in developing countries (WHO 2013). Global health authorities and specialists argue that cervical screening programs in developed countries have significantly reduced the impact of this cancer. In developing countries, in contrast, limited access to effective screening and poor treatment has meant a higher rate of death from cervical cancer. In Colombia, the National Cancer Institute estimates that 7000 cases of cervical cancer are diagnosed every year, 1 in 25 women will have cervical cancer at some point in their lives and 2300 women will die of this disease. Cervical cancer is the second cause of female mortality by cancer in the country.

Cervical cancer is strongly associated with the persistent and untreated infection of specific types of HPV (most frequently types 16 and 18). There are currently two vaccines that protect against both HPV 16 and 18, which are associated with 70 percent of cervical cancers (WHO 2013): Gardasil produced by Merck and Cervarix by Glaxo SmithKline (GSK).[1] In 2012 the Colombian government introduced Gardasil into the expanded program of immunization. According to the Ministry of Health, since that year 3 million girls have received the vaccine in Colombia, while 120 million doses have been delivered worldwide.

During the first vaccination cohort in 2012 only a couple of cases of adverse effects associated with the vaccines were made public in Colombia.

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[1] Gardasil protects against four types (tetravalent) of HPV: HPV 6 and 11 associated with genital warts, and HPV 16 and 18 associated with cervical cancer. Cervarix protects against two types (bivalent) of HPV: HPV 16 and 18.

Most journalists and public accounts of the vaccine focused on its benefits in terms of cancer prevention and extension of health care to vulnerable populations. However, in August 2014, in the town of Carmen de Bolívar, hundreds of girls were hospitalized after being vaccinated. This crisis has in many ways changed the public perception of HPV vaccines in Colombia, rendering visible a set of tensions in the relationships between trust, risk, sexuality, anticipation and evidence. The Carmen de Bolívar adverse effects outbreak demanded public mobilization of a set of narratives and technical repertoires about evidence production that often remain invisible.

As the different contributions of this book have shown, drugs not only produce sexed/gendered identities for those who are supposed to take them, but also coproduce imaginaries and representations about these identities that circulate among the different actors involved in their management and governance. This chapter illustrates some of the tensions that the introduction of HPV vaccines has produced in Colombia. I offer an analysis of the ways in which HPV vaccines are "sexed" and "desexed" in connection with broader power relations and representations about gender, sex and legitimate knowledge. The objective of HPV vaccination in Colombia has been the prevention of cervical cancer by vaccinating girls between 9 and 15 years. An emphasis on cervical cancer has rendered other cancers invisible. When the effect of HPV on male health has been discussed, authorities have argued that the protection of men against HPV infection would be reached by the "herd effect" of female vaccination. These assumptions have framed vaccination campaigns and HPV vaccine advertisements, as well as the technical justification for this health intervention, particularly the cost-effectiveness analysis and the knowledge that is assumed as evidence.

Additionally the relationship between HPV vaccines and sex has sometimes been strategically used by health authorities and experts to enhance the value of vaccination, while at other times it has been used to avoid debate and parental concern, particularly in relation to girls' sexuality. While in technical literature and decision-making scenarios, genital warts and the understanding of HPV contagion as a sexually transmitted disease (STD) played an important role in the justification of publicly funded vaccination, in campaigns and public arenas HPV vaccines are desexualized. They are portrayed as drugs against cancer that promote social equity and tools of female empowerment.

Some of these representations and tensions between sex, gender and HPV vaccines have been documented in different locations (Aronowitz 2010; Carpenter and Casper 2009a, b; Colgrove et al. 2010; Epstein 2010; Mamo et al. 2010 in the United States; Mishra and Graham 2012 in Canada; Ramogola-Masire 2010 and Livingstone et al. 2010 in sub-Saharan Africa; Hanbury (Chap. 8, this volume) in the UK; and Lindén (Chap. 6, this volume) in Sweden). Two questions emerge from this set of works. First, what is particular or country specific in the introduction of HPV vaccines? Second, do geopolitical classifications really matter in the configuration of these drugs and, if so, how? In this chapter I will try to answer these questions by presenting some particular tensions around the introduction of HPV vaccines in Colombia that are related with the historical and material configuration of cervical cancer in the country, particularly with the relationship between this disease and social difference, and the different intersections between gender, nation, class and race that entails.

In this account, I will rely on material gathered from public campaigns, media and public accounts of vaccination practices, and medical and legal discussions in Colombia. My goal is to present how the analysis of local and national situated experiences can contribute to the understanding of the global connections that support drug circulation and the shaping of "healthy" subjectivities. Drawing on postcolonial science and technology studies (STS) sensibilities (Harding 1993) this chapter aims to understand the ways in which such global connections are produced. An account of these connections provides a way of avoiding an exotic portrayal of the south by showing the relationships between multiple locations in the configuration of pharmaceutical biographies (Carpenter and Casper 2009b). This chapter aims to contribute to the understanding of sexing drugs by showing how they interact between different social and power relations and in connection with particular ways of producing knowledge about them.

1 Anticipation, HPV Vaccines and Intersectionality: Coproducing Drugs and Subjectivity

Most of the existing work on HPV vaccines explores contemporary transformations in health care such as its biomedicalization (Connell and Hunt 2010), pharmaceuticalization (Mamo and Epstein 2014) and the rise of anticipation regimes (Adams et al. 2009; Carpenter and Casper 2009a, b). Connell and Hunt (2010) have noted HPV vaccine campaigns show the intertwining of "regulatory discourses of moralization and medicalization in an era of biopolitics" (Connell and Hunt 2010: 66). Expert discourses and self-regulation converge in HPV vaccination narratives in contexts of neoliberal governance of health care (Connell and Hunt 2010: 66).

Adams et al. (2009) have proposed the concept "regime of anticipation" to describe a contemporary mode of technopolitical governance characterized by its obsession with the future and the reshaping of the present through anticipation (Adams et al. 2009: 260). These regimes imply a change from regimes of truth to orderings in which anticipation is constituted through modes of prediction and instrumentality. These regimes have affective dimensions, in which the subjects are engaged in affective economies of fear, hope, salvation and precariousness "oriented temporally toward futures already made 'real' in the present" (Adams et al. 2009: 260). Different authors (Adams et al. 2009; Carpenter and Casper 2009a, b; Mishra and Graham 2012) have noted that HPV vaccines are a good method of tracing the ways in which these regimes are constituted and how they operate in health care.

First, HPV vaccines are distinctive from other vaccines. While conventional vaccines rely on politics of contagion and containment, HPV vaccines have been framed as an anticipated intervention into cancer (Carpenter and Casper 2009b). Advertising and other campaigns have emphasized the role of HPV vaccines in the prevention of cervical cancer rather than in the control of an STD. Second, HPV vaccines are a new gendered technology built from the ambiguous relationship between cervical cancer and HPV. This vaccine has generated an epistemological and practical confusion of the relation between cervical cancer and HPV that has contributed to sexualizing and to gendering political debates: "Because the HPV vaccine's target is sexually transmitted, it provokes longstanding controversies swirling around sex, gender, and women's bodies in the US" (Carpenter and Casper 2009a: 896).

HPV vaccines also constitute an interesting case in which to trace the ways pharmaceuticals interact and transform their political and cultural landscape "(re)shaping the pharmaceutical's life course in turn" (Carpenter and Casper 2009a: 896). As Mishra and Graham (2012) have noted, the reception of new vaccines is the result of "a complex interplay of science, marketing, healthcare policies and practices, media representations and social perceptions" (Mishra and Graham 2012: 64).

Most social science research about the reception of HPV vaccines has privileged the analysis of marketing campaigns, media and political discourse to trace tensions that these pharmaceuticals entail (Carpenter and Casper 2009a, b; Aronowitz 2010; Colgrove et al. 2010; Epstein 2010; Mamo et al. 2010; Ramogola-Masire 2010; Livingstone et al. 2010; Mishra and Graham 2012; Lindén 2013). For instance, the book *Three Shots at Prevention* edited by Keith Wailoo, Julie Livingston, Steven Epstein and Robert Aronowitz (2010) provides a collection of works about the impact of HPV vaccines, mainly in North America and Europe. Two of the chapters analyze the introduction of these vaccines to Africa in the context of international cooperation in global health (Livingstone et al. 2010; Ramogola-Masire 2010). Little work has critically examined how these tensions are enacted in the processes of selection and decision making undertaken in technical committees and the role of "evidence" in constituting the HPV vaccine as a matter of public interest. Moreover, few works have discussed the impact of HPV vaccines on the "Global South," particularly in the so-called middle-income countries.

In what follows, I would like to present the ways in which social difference intersects the production of evidence in the introduction of HPV vaccines. This description pays particular attention to the intersectionality in which HPV vaccines are entangled and the ways in which these relations are reshaped by the introduction of this technology. As Collins has noted, "the term intersectionality references the critical insight that race, class, gender, sexuality, ethnicity, nation, ability, and age operate not as unitary, mutually exclusive entities, but as reciprocally constructing phenomena that in turn shape complex social inequalities" (Collins 2015: 2).

This kind of sensibility is important in tracing how sex, gender, drugs and evidence are coproduced in relation to the historical and material context of countries that have been represented as peripheral to the centers of economic and knowledge production (Harding 1993), for example, Colombia. HPV vaccines are introduced in Colombia in a context in which gender, sex, class and race have played an important role in the production of imaginaries about the relationship between cervical cancer and inequality. Such entanglement is affected by the introduction of HPV vaccines. Different works in STS (Harding 1993; Haraway 1997; Weasel 2004; Shim 2005; Epstein 2007; Grzanka 2014) have noted the importance of analyzing expertise and scientific knowledge in the production and reproduction of social difference and inequality.

As Collins notes, the challenge is to relate specific knowledge projects to historically produced power relations, attending to the ways in which they mutually shape each other. In this regard, intersectionality can be understood as a sensibility, a way of approaching social difference by moving beyond a mono-categorical focus on racial, gender or class inequality "to encompass multiple forms of inequality that are organized via a similar logic" (Collins 2015: 5). As I present in the following sections, the ways in which sex and gender are produced in the introduction of HPV vaccines in Colombia are deeply entangled with other dimensions of social difference such as class and race. I explore these relations through the analysis of a diverse set of materials from textual analysis of technical and scientific literature, press and news, to interviews with advisors and members from the National Committee of Immunizations practices in Colombia. These different objects allow me to portray the tensions that the introduction of these drugs creates in different scenarios, from policy arenas to media and vaccination practices.

2 Introducing HPV Vaccines in Colombia: Not Just a Matter of Evidence and Efficiency

In 2006 the Food and Drug Administration (FDA) approved Gardasil (HPV quadrivalent vaccine produced by Merck) and, two years later, Cervarix (bivalent vaccine) produced by GSK. In 2009 INVIMA—the Colombian food and drugs authority—approved Gardasil, and one year later Cervarix obtained registration. After that, private clinics and medical insurance companies began to promote the vaccination of their female patients. The cost of the vaccine, approximately US$150 per dose, limited access to the urban middle classes. Since 2010, different local authorities started discussions about the importance of organizing public, free vaccination programs. Bogotá, the capital of the country, and Casanare, a wealthy oil-producing state, were the first regions to approve and start pilot vaccination programs. At the same time, the Expanded Programme of Immunization [Programa Amplicado de Immunización, PAI in Spanish] on behalf of the national government came to an agreement with Universidad Nacional de Colombia to develop a technical study about the cost-effectiveness of HPV vaccines. This study considered the effectiveness of a national screening program and the international cost of vaccines in the market (Gardasil and Cervarix), concluding that at the international prices at the time (2009), a national HPV vaccination program would not be cost-effective (UNAL 2009: 60).

Many voices within the medical community expressed disappointment with the conclusions of that study. However, a legal class action was the event that forced the government to reconsider the results. In December 2010, Mrs. María Teresa Tovar Rojas brought a class action against the Ministry of Health to protect the rights to public health and security that were breached because of the non-inclusion of HPV vaccines into the Mandatory Healthcare Plan (POS). As result of this class action, the Court recognized that the Right to Public Health was breached by omission, establishing a deadline of three months after the ruling to complete new cost-effectiveness studies. Finally, the Court ruled that if the HPV vaccine was found to be cost-effective, the ministry had one month to include it in the POS. The Ministry of Health and the Health Regulatory Commission appealed this ruling and the case was transferred to Council of State. In parallel to this legal process, in 2011 Congressman Luis Enrique Salas Moisés proposed a Bill in the Colombian Congress in order to guarantee free and mandatory HPV vaccination.

At the end of that year, the Ministry of Health asked Universidad Nacional for a second technical study. This second study included an analysis of the burden of genital warts and concluded that at the international prices of that time (2011), an HPV vaccination program using Gardasil would be cost-effective. Accordingly, the National Committee of Immunization Practices on behalf of the Ministry of Health approved the introduction of Gardasil into the expanded program of immunization. Officially the national vaccination program against HPV started in August 2012. The president of Colombia, Juan Manuel Santos, presided over the campaign launch.

In 2013, the Colombian Congress approved Act 1626 (2013) to guarantee an item from the national budget to support long-term HPV vaccination programs. In the same year the first cases of adverse effects were made public in the national media. Despite these cases, the program was widely praised by politicians, medical communities and journalists. In 2014 the program became seriously questioned after the Carmen de Bolívar crisis in which hundreds of girls were hospitalized after being vaccinated against HPV. This generated a huge controversy in the media and triggered local protests. Since then, through bodies of experts, the Colombian government has defended the vaccination program and argued that the evidence supports the safety and effectiveness of the vaccine.

In Colombia, evidence and efficiency have been claimed as principles for the health-care system since its “modernisation” in the 1990s (Act 100 [1998], Agreement 117 [1998] and Agreement 232 [2002]). This regulative framework has presented an ideal of policy based on efficiency, evidence and the proper management of information. Accordingly a sound policy is the result of the correct data and the right calculation tools. Despite this normative approach, the first attempts to create an institution devoted to the collection and definition of evidence for health-care policymaking did not happen until 2007 with the establishment of the CRES (Health Regulatory Commission). This institution disappeared in 2012 after a debate about its technical competence and was replaced by the IETS (Institute of Health Technologies Assessment) a public–private organization based on the model of the National Institute for Health and Care Excellence in the UK.

In practice, just a small number of procedures and technologies have been evaluated following evidence-based medicine (EBM) standards in Colombia. However, among these, vaccines have had an important place. PAI has regularly used cost-effectiveness analysis and systematic reviews for decisions about the introduction of new vaccines in the country. However, because of the potential cost of a vaccination program against HPV, the technical studies to determine the cost-effectiveness of these vaccines were particularly detailed compared with others. They involved a complex gathering of epidemiological data and costs in order to demonstrate the value of vaccination in preventing cervical cancer. The result of these calculations is enacted as evidence (Maldonado 2015).

In the process of producing evidence, different relationships are produced between vaccines and those who are supposed to take them. In what follows I will present some of the connections that the production of evidence establishes between social difference based on sex, gender, class and race and the politics of contagion and prevention of cervical cancer and HPV infection. First, I will revisit the historical narratives that have linked cervical cancer and social difference, showing how such relation has been enacted in Colombian medical discourses. Second, I will show the role that sex played in the production of evidence about the pertinence of HPV vaccines and the ways in which such relations were rendered invisible, once the vaccine was approved, in public arenas. In such processes, sex and gender are separated. Health authorities have feminized HPV vaccines by hiding their connections with sexuality. Finally, I present some tensions between experts' evidence and parents' and public representation of vaccination that have escalated in Colombia in connection with the sexing of HPV vaccines.

3 Cervical Cancer: Social Difference and Sexuality

Cervical cancer epidemiology has integrated categories such as sexuality, race and class throughout its history. Such classifications have appeared iteratively in the medical discourses about this disease over the last 150 years. Poverty, sexual behavior and race are part of the repertoire of risk factors that characterize a disease in which it is impossible to distinguish a proper cause. Because cervical cancer historically has been characterized as a disease that embodies inequity, gender differences and power asymmetries, epidemiological and medical research on cervical cancer attributed it to social groups and women in situations of marginality, and more recently to underdevelopment (Löwy 2011). As Löwy notes "cervical cancer no longer occupies an important place on the list of diseases dreaded by Western women. Breast cancer is everywhere, but cervical cancer is barely visible" (Löwy 2011: 17). Nowadays cervical cancer is considered a highly preventable disease. However, while prevention strategies have been effective in terms of public health in the "North," cervical cancer has become a disease of the developing world. These categories have shaped epidemiological research, data and policy. Epidemiologic versions of class, race and gender have played an important role in the identification of particular groups as sources of risk and pollution (Epstein 1996: 49).

One of the first epidemiological portrayals of cervical cancer was made by the Italian physician Domenico Rigoni-Stern (1842). He found a statistical relation between sexual behavior and the development of cervical and uterine cancer (Scotto and Bailard 1969). Such relationships had been reported before by different physicians who observed that cervical lesions were less frequent in nuns than among married women and prostitutes. In contrast, breast tumors were more frequent among nuns (Löwy 2011: 130). During the late nineteenth century a set of risk factors for the disease were gradually developed. Frederick Hoffman (1896), in his study *Race Traits and Tendency of the American Negro,* highlighted the relation between "exacerbated sexual behaviour," "multiple pregnancies" and cervical cancer, and in his analysis these features were associated with black populations (Löwy 2011: 130). These narratives produced an image of cervical cancer as a consequence of immoral behavior. During the first half of the twentieth century, class as a category of classification became important in defining cervical cancer dynamics, as well. However, within this multicausal narrative it is also widely recognized that poor women are also affected by frequent pregnancies, inadequate medical care and harsh life conditions that make them vulnerable to cancer.

HPV has reshaped understandings of cervical cancer, figuring sexuality once more as the key element in the disease. Although since the beginnings of epidemiological research sexual contagion was considered as a possible transmission route for cervical cancer and genital-related agents, such as the herpes simplex virus (HSV), HPV and human sperm were considered possible causes of cervical cancer, it was not until the 1980s that the technology to trace molecular DNA allowed a “complete” model to be assembled of the natural history of cervical cancer based on the understanding of HPV proteins’ role in causing cervical mutations. Nevertheless, women’s and men’s sexual behavior played an important role in the understanding of cervical cancer in the 1970s. For the first time a number of large epidemiological studies around the world determined the role of sexually transmitted infections in the development of cervical lesions.

These studies were supported by the WHO and its research institute IARC (International Agency for Research on Cancer) (Muñoz et al. 2003). At this time HSV, cytomegalovirus and HPV were considered possible agents (Muñoz et al. 2003). These studies constituted the basis for the molecular biological research into a possible connection between an infectious agent and cervical cancer. In 1982 Harald Zur Hausen demonstrated a causal connection between infection by two types of HPV (16 and 18) and the development of cervical lesions and neoplasia. Although HPV is depicted as a singular and stable entity in public and policy arenas, it denotes a family of viruses. More than 100 types of HPV have been identified, and approximately half of them infect the genital tract. Approximately 30 percent of these have been associated with the development of cervical cancer.

Pharmaceutical companies have presented HPV 16 and 18 as the main high-risk types for cervical cancer, selecting these types as the targets for their vaccines. However, there are another 15 high-risk types that have been identified as potential agents of cervical cancer (HPV 51, 69, 82, 39, 45, 59, 68, 70, 16, 31, 33, 35, 52, 58, 67) (IARC 2007: 53). As a matter of fact, in some regions these types have a greater incidence than HPV 16 and 18. For instance, in sub-Saharan Africa where HPV 42 is the most prevalent, current HPV vaccines could be less effective in reducing cervical cancer. These types have been also found in anogenital and oropharyngeal and epithelial cancers (IARC 2007: 56). However, in terms of health policy, this link has remained invisible, which has led scholars such as Epstein (2010) to note that such marginality may be related to their perception as "gay" cancers.

HPV has been transformed in this process, changing from a relative innocuous agent—HPV is the commonest infection worldwide, and in the 99 percent of cases, the body develops a natural immune response—to a carcinogenic menace and a public health concern (IARC 2007). Once cervical cancer was redefined as an STD, now associated with HPV, "the links between social class and cervical cancer were attributed—again—to differences in sexual mores" in men and women (Löwy 2011: 141). Cervical cancer nowadays is understood basically as the result of an STD (HPV infection): other factors have been rendered invisible.

3.1 Locating Difference: The Cancer of Underdevelopment

The contemporary portrayal of cervical cancer in the global south has been framed by policymakers and health authorities (WHO, Pan American Health Organization [PAHO], local Ministry of Health) as a matter of economic and social development. From a technocratic perspective an implicit conclusion is that improvements in the technical infrastructure of screening programs will make them as efficient as those in industrialized countries (Piñeros et al. 2007; Löwy 2011: 166). However, such technical infrastructures have faced the social, cultural and political features of the contexts in which they are represented. Many of these problems are related to serious issues of gender equity. Women bear the material and embodied consequences of asymmetric and unfair social, political, economic and affective relations (Gregg 2011; Livingstone 2012).

Cervical cancer has often been stigmatized because of its relation to sexuality. And in Colombia, cancer is presented in public health campaigns as a consequence of an uncontrolled sexuality and women as victims of men's promiscuity. Such narratives have been widely reproduced in information materials. In Colombia, public health strategies for the control of cervical cancer have been focused on "populations at risk," those groups whose ways of living correspond with the risk factors defined by epidemiological research. These factors have mainly highlighted the relation between socioeconomic marginality and sexual behavior. In a guide regarding the risks of cervical cancer developed by PAHO in 1994 for Colombia, for example, one could have read:

> Regarding the risk of cervical cancer it is necessary to highlight the wider cultural acceptance of polygyny, temporal unions and the definition of masculinity in relation to the quantity of sexual relations with different women. (INC 1994: 3)

Despite cervical cancer and HPV contagion being present in the whole population, cervical cancer is defined as a problem of particular segments of society by attributing risk factors to it. Many of the so-called risk factors describe behavior that is common to large parts of the population, regardless of their social and economic resources. However, to the extent that some marginalized groups are stigmatized, these factors are recognized only in them.

In Colombia, campaigns to promote a national cervical screening program have reinforced these imaginaries. In 2008 the Colombian National Cancer Institute (CNCI) developed a campaign to communicate the risk factors for cervical cancer and to promote periodic screening as the best strategy for prevention. One of the key elements of this campaign was a graphic soap opera (Fotonovela) about a "working-class" couple who faced the husband's infidelity and the wife's abnormal Pap test results at the same time. This story gathered together narratives such as that women were victims of uncontrolled male sexuality, cervical cancer thrived in poor settings and the disease entailed stigma.

HPV vaccines were introduced in this context. The first pilot programs in Colombia focused on populations at risk. Bogotá's earliest campaign of vaccination was directed at girls from working-class neighborhoods and was extensively promoted as a health equity intervention. However, the most extreme case was the vaccination program of Casanare—a Colombian region—in which the targets were daughters of sex workers. Casanare's health authorities perceived that these girls were at higher risk of having cancer because of their mothers' work. As is noted in an interview conducted with one of the members of a national committee of immunization practices:

> Well, we made a study with Dr. X and Dr. Y to evaluate the activities for the control of cervical cancer (…) we found that cervical cancer was considered a priority. Local health authorities had decided to buy vaccines; they started to invest money in immunization. Obviously, because of the high cost of the vaccine they decided to immunize populations at risk. For us such a strategy was not the most appropriate; we thought it was a misunderstanding of the idea of being at risk. For instance, they considered the daughters of prostitutes as a population at risk. Such a program not only stigmatized these girls, it also did not guarantee its sustainability or equity.

Nevertheless, once the program aimed to reach a general and wider population, these strategies and their associated narratives changed toward a more general and desexualized account of risk. The new narrative has emphasized this as a vaccine against cancer rather than a strategy of prevention of STD infection. Such a transformation can be followed in technical studies to introduce the vaccine and in public campaigns to promote the vaccination.

4 Sexing by Numbers, Desexing by Images: Expert and Public Displays of HPV Vaccines

The definition of cervical cancer as an STD and of vaccination as a tool of prevention shaped the models and the studies to define HPV vaccines' cost-effectiveness and pertinence. Epidemiology had noted cervical cancer displayed a profile similar to STD (Bosch et al. 2002: 246). During the second half of the twentieth century, research around cervical cancer was focused on finding a cause linked to STD; syphilis, gonorrhea and HSV type 2 were hypotheses. Even sperm was considered as a possible cause, the so-called male factor (Reid et al. 1978; Reynolds and Tansey 2009).

The data and parameters to run models and cost-effectiveness analysis in Colombia depended heavily on Bogotá's cohort study (1997–2007). This was a longitudinal study developed by the CNCI. The research followed a cohort of 2000 working-class women over ten years in order to detect the incidence and prevalence of HPV infection, the types of virus involved and the transitions toward cervical lesions and cervical cancer (Muñoz et al. 2004).

These data were produced in a context in which the boundaries between research and health care are hardly distinguishable. The CNCI has been simultaneously a research center and a "charitable hospital" in which the promise of health care has been a strategy to recruit patients for studies (Maldonado 2015). The relationship between cervical cancer and social difference, presented in health campaigns, is reproduced in the construction of epidemiological data. There is a tacit connection between exacerbated sexuality, poverty and disease in the risk factors to identify individuals and to produce data about incidence and prevalence of cervical cancer.

In cost-effectiveness analysis, HPV vaccines have been basically understood as prevention tools for cervical cancer. Reference to other cancers related to HPV infection—such as throat and anal cancer—is marginal in policymakers' discourse and technical reports, though sometimes it is used to strengthen the link between cancer prevention and vaccines. Descriptions of other types of cancer have strengthened the image of HPV as a powerful carcinogenic agent; however, most of the time it remains invisible because of its relation with non-heteronormative sexualities, particularly in connection with anal and oral sex.

Genital warts were another element that significantly contributed to the sexing of HPV vaccines. The consideration of genital warts as a public health problem has been controversial (Maldonado 2015). For years this was a condition considered benign; however, it became a "health" problem in close connection with the molecular design of Gardasil and its prevention of HPV 6 and 11 infections. Protection against genital warts became an advantage for Gardasil compared to its competitor, Cervarix. In parallel to the licensing of Gardasil, the economic analysis of the burden of genital warts was undertaken to show the possible impact of this vaccine in terms of cost reduction for health-care systems in several countries (Hillemanns et al. 2008).

In Colombia, regional health authorities have claimed genital warts are a serious clinical issue, particularly in those towns and provinces affected by war. The army medical service reported that genital warts were a common condition in soldiers. The political and clinical interest in genital warts contrasts with the lack of studies and epidemiological data about their incidence, costs and treatment. This is not a problem exclusive to Colombia; information about the incidence, prevalence and treatment costs of genital warts is relatively scarce compared to the data about other cancer diseases associated with HPV infection. Even the German study used as “evidence” to define the parameters of the cost-effectiveness model in relation to genital warts noted the difficulties of gathering information about genital warts in Germany, where the study was conducted, and this research team decided to calculate the incidence and costs of genital warts through the analysis of a statically representative sample (Hillemanns et al. 2008).

The consequences of introducing genital warts into the calculations of the national immunizations committee were very significant. First, they increased the value of HPV vaccines, because of the estimated costs and burden of disease that could be prevented through vaccination. Second, they constituted a differential between vaccines. Only Gardasil prevents against cervical cancer and genital warts. Third, the emphasis on genital warts not only increased the value of the tetravalent vaccine (Gardasil) but also overshadowed the possible impact of this vaccine on other cancers, most of them related to non-heteronormative sexualities.

The committee’s decision to extend the vaccination program from cervical cancer to genital warts involved the introduction of new factors which were harder to control, particularly in promoting a vaccine against an STD where the target is girls between 9 and 12 years. For health authorities, the public perceives cervical cancer basically as a cancer, a fatal disease in which women are victims, while genital warts are viewed merely as a nasty STD. Such a patronizing attitude is visible in advertisements and public health campaigns, in which health authorities have hidden the sexual dynamics of infection and focused on cancer prevention.

In all these different scenarios cost-effectiveness has been the key issue that justified the inclusions and exclusions that HPV vaccines entail. Cost-effectiveness has justified the definition of girls as the population target and the exclusion of boys from the risks and benefits of these drugs. The promise of an extended protection to boys through the herd effect from girls' vaccination renders visible the heterosexual sexualizing of HPV vaccines and its connection with economic rationality. This cost-effectiveness analysis has also been a key instrument in the sexualizing and desexualizing of cervical cancer and HPV vaccines.

Nevertheless, such sexualizing is limited to decision-making and experts' arenas. In media and vaccination campaigns, the Ministry of Health and the Expanded Programme of Immunization have tried explicitly to desexualize HPV vaccines, presenting them as an anticipated treatment against women's cancer and as a means of empowerment for girls. As a result, genital warts, a key factor in the process of decision making, fall into the shadows as "a technical detail." Meanwhile, cervical cancer and gender inclusion is integrated in the presentation of the vaccine in public arenas and the media.

Instead, in Colombia, politicians and health authorities have promoted vaccines as a tool for women's empowerment and health equity intervention to prevent cancer. Additionally, political speeches and vaccination campaigns have used the multicultural repertoire that has shaped the political rhetoric during the last 20 years. This point is illustrated in the campaign material developed by the Ministry of Health. The campaign "Que vivan las mujeres" [Viva women!] explicitly avoids any reference to either sexuality or HPV. Instead it promotes the vaccine as a cure for cervical cancer that protects the lives of Colombian girls regardless of their region, class or race.

A 30-second-long promotional video of the campaign shows girls singing and playing. These girls are at school. Some of them are "having fun" in the laboratory, others playing sports and others playing instruments (drums and guitars). The video is intended to show the diversity of Colombian girls, and different ethnicities are portrayed: Indigenous *emberas*, Afro-Colombians, mestizo and white girls; one of the girls is even in a wheelchair. The video illustrates the main political message behind HPV vaccination: it is an egalitarian policy and a matter of social justice. As Collins has noted, contemporary racial configurations imply hierarchies in which color-conscious and color-blind racial formations persist and coexist (Collins 2015: 4).

Since the 1991 Political Constitution, the state has embraced an egalitarian discourse that defines Colombia as a multicultural and pluri-ethnic nation. Such egalitarian ideals contrast with the uneven development of Colombian regions. In some regions, up to 68 percent of the population is considered poor (Chocó 68 percent; Cauca 62.1 percent; Córdoba 60.2 percent, La Guajira 58.4 percent), while in Bogotá fewer than 11.59 percent live in poverty. The poorest regions in the country have predominantly indigenous and African populations. As Lindén (Chap. 6, this volume) has noted, public narratives about HPV vaccines in campaigns and advertisements produce material-semiotic connections between girls' embodied subjectivities and the "natural" imaginaries of the nation. In the case of Sweden, such discourses associate girls' health with the Swedish landscape, nature and a healthy and outdoorsy living style. In Colombia, cultural and ethnic diversity are presented in intimate connection with the diverse and fragmented natural landscape of the Colombian regions, in which different traditions, races and cultures harmoniously coexist. In contrast with this narrative of unity, Colombia has historically been a fragmented land and a divided society (Palacios and Safford 2002).

As I have previously noted, most journalists' and public accounts of the vaccine focused on its benefits in terms of cancer prevention and the extension of health care to vulnerable populations. However, the Carmen de Bolívar outbreak changed public perception of HPV vaccines in Colombia, revealing a set of tensions in the relationships between sexuality, trust and evidence. In Sect. 5 of this chapter I present the ways in which this event demanded the public mobilization of evidence in a context of distrust and social protest. Such confrontation illustrates the consequences of HPV vaccines' sexing and desexing and the limitation of state paternalism and its response to social protest and the erosion of public trust.

5 Hysteria, Social Protest and Evidence as Violence

September 2014 was a month full of news about HPV vaccines in Colombia. This subject, which previously had barely attracted the attention of journalists, suddenly became the center of an enormous controversy. The trigger was a strange outbreak of allegedly adverse vaccine-related effects in a small town of the Colombian Caribbean coast, Carmen de Bolívar. During the month of August, days after the vaccination campaign, hundreds of girls were hospitalized. These girls had symptoms ranging from fainting to numbness in the hands and headaches. Although some cases of adverse effects had been reported before, the Carmen de Bolívar outbreak concentrated the attention of media, politicians and governmental institutions because of the number of girls affected and the mobilization of their parents demanding state action.

The Carmen de Bolívar outbreak revealed the growing division between political parties in relation to conceptions and governance of human life. The conservative groups that had traditionally opposed the voluntary termination of pregnancy have gradually directed their attention against HPV vaccines. Political movements such as "Catholic vote Colombia" have argued that the HPV vaccine does not protect but rather hurts the young by promoting promiscuity. At the same time, actors who identify themselves as politically and culturally liberal (some journalists, women's movements, public health experts) have supported HPV vaccination and the scientific evidence that legitimizes their use. Journalists like Hector Abad Faciolince have denounced the Colombian General Prosecutor—an important Catholic right-wing politician—for encouraging parents, often from Catholic schools, to discredit the serious effects that the HPV vaccine could be causing.

In this context, the definition and attribution of evidence has become a critical matter and zone of dispute. In cases where the vaccine has been criticized for its possible adverse effects or its lack of efficacy, the government and the health authorities have reacted by affirming that evidence is on their side. This was the initial reaction of the Colombian government when the Carmen de Bolívar outbreak reached national and international media. The government called the reported adverse effects manifestations of "collective hysteria" (*Semina* 2014). The local community received such declarations angrily and started a protest that ended in riots and clashes with the police. After this, the Ministry of Health called a committee of experts (comprising almost all the members of the NCI) to assess the situation. Toxicologists were sent to Carmen de Bolívar and the health authorities changed their language, medicalizing the social tensions generated by the vaccination. The description of this phenomenon changed from "collective hysteria" to a "psycho-social disease" (Caracol Radio, September 24, 2014).

National health and toxicology experts traveled to the town to collect blood samples and investigate possible environmental hazards. Their conclusion was that there was no evidence that the vaccine was the cause of the girls' symptoms. They argued that these results verified the "extensive international testing and regulation globally" that recognized the safety of the vaccine. However, these conclusions had little impact in calming parents' and community concerns. A blog published in the local newspaper *El Heraldo* describes people's disillusionment with the government and the expert evidence. The column echoes a traditional song (a cumbia) that sings of the beauty of Carmen de Bolívar's women. The author modified the song's lyrics to tell the drama of the outbreak:

> Dear Carmen, lovely land, there are shadows and nightmares under your sky. It is useless for you to hide amongst the Mountains of Maria. There is a voice about what is happening, here in the intimacy of your streets garnished with virgins. Your virgins of flesh are decaying. With the pain and tears of 439 girls vaccinated against a sexual transmitted virus. Your people are solving a puzzle and blame the government. Because after months of faintings and the dance of psychological explanations and the laboratory analysis just one diagnosis is clear: No one knows the truth about what is happening, but everyone knows it stinks.[2]

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[2] "Carmen querido, tierra de amores, hay sombras y pesadillas bajo tu cielo. De nada sirve que te escondas entre las faldas verdes de los Montes de María. Se corre la voz de lo que está pasando aquí abajo, en la intimidad de tus calles adornadas con estatuas de vírgenes. Tus vírgenes de carne y hueso se desmoronan. Con los pedacitos de llanto y dolor que van dejando regados 439 niñas recién vacunadas contra un virus de transmisión sexual, tu gente arma un rompecabezas que acusa al Gobierno. Porque los meses de desmayos y la danza de explicaciones psicológicas y análisis de

This outbreak has highlighted serious problems beyond their possible adverse effects in the delivery of vaccines. In many cases, parental consent had been taken for granted, while other families have reported they were told by nurses at schools that if their daughters did not get the vaccine, they could lose social benefit payments (*El Heraldo* 2014.) Other parents have noted they were not aware of the connection between cervical cancer and HPV, or that HPV was a sexually transmitted virus. If they had known about the nature of the vaccine, they would not have consented to their daughters' vaccination. Many have claimed that their daughters were virgins, thus they did not need the vaccines, nor should they have been exposed to any risk (*El Heraldo* 2014.)

The case of Carmen de Bolívar has initiated an important debate about vaccine safety and effectiveness. The government and scientific experts point out that they have weighed the scientific evidence, and argue that HPV critics have based their position on opinion and moral prejudice (La W Radio, September 26, 2014). In this public debate, evidence has meant having data, numbers, expert and institutional support. The Colombian writer Héctor Abad Faciolince summarizes such evidence in a column that backs HPV vaccination:

> There are rigorous studies around the world about the possible adverse effects of the vaccine. From 67 million of doses, 25,000 adverse effects have been reported. From these 25,000, 92% were not serious effects (fever as in my daughter, or skin redness). The rest, 2000 cases were serious effects, that is 0.003% of the cases, a bit higher than the placebos. The World Health Organisation WHO is right when they affirm that the HPV vaccine is safe. The same is said by one of the few Colombians who deserves a Nobel prize in medicine: Dr. Nubia Muñoz. (*El Espectador* 2014)

Indeed Dr. Nubia Muñoz has embodied the voice of science and evidence in this debate. This Colombian epidemiologist was head of the Department of Cancer Epidemiology at WHO's IARC. She directed an important part of the epidemiological studies that allowed the identification of the causal link between HPV and cervical cancer. Muñoz was a

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laboratorio solo dejan un diagnóstico claro. Nadie sabe de verdad qué pasa, pero todos saben que apesta."

special guest at the vaccination launch and has been often interviewed by international and national media. In one of her most recent interviews (October 5, 2014), she passionately defended the evidence regarding the safety and effectiveness of HPV vaccines. She declared that international agencies such as WHO, PAHO, FDA and the European Medicines Agency have recognized that the HPV vaccine is safe and that there is no evidence showing that the HPV vaccine generates autoimmune diseases (Guillain-Barré, multiple sclerosis, etc.). However, her answer to a question about the opinion of a toxicologist who found a relation between the HPV vaccine and the development of transverse myelitis offers a way of understanding evidence and how it differs from scientific knowledge:

Journalist: In Cali a girl became paralysed by transverse myelitis, according to a toxicologist because of the aluminum in the vaccine …

NM: I don't believe you … show me the data and we will see. I have not seen the study, but it is impossible that just one doctor, who may be outstanding, can say this with just one case against the opinion of committees of experts that have reviewed the evidence in thousands of cases. (*El Pais* 2014)

As she notes, the production of evidence has to do with the practice of reviewing, the methodical selection of "thousands of cases" and their discussion and legitimation by a technical committee, a particular group of experts with authority on that matter. These technical committees have a monopoly on the definition of evidence. By means of calculations, they divide and select technical information that acquires a higher status as evidence. The production of evidence is an effort to organize a diverse, contradictory and messy universe of technical information in order to enact a unique and clear voice for science. These practices have had an important impact on the shaping of contemporary health-care governance by means of the promise of clear and reliable decision making. At the same time, the use of these methods of analysis and organization has raised concerns among medical and patient communities about the limitations that the very concept of evidence imposes on scientific knowledge.

The importance of evidence production in the governance of contemporary health care has been recognized by patients' organizations, and some of these have critically appropriated this framework to enhance their own claims. As Madeleine Akrich and colleagues have noted, the use of evidence in health-care decision making implies a disjunctive between experiential and formalized knowledge (Akrich et al. 2014: 129). While policymakers have adopted a formalistic approach to evidence, patients' organizations and some medical communities have used the concept of evidence to express the authority of their experiential knowledge (Akrich et al. 2014: 129; Rabeharisoa et al. 2014: 112). In the case of patients' activism "knowledge and evidence play a pivotal role in creating an interface for engagements between users and professionals" (Akrich et al. 2014: 129).

Parents' reactions to the Carmen de Bolívar outbreak show their distrust of EBM and public health authorities. Their actions have been an expression of the lack of confidence in the Colombian state. Unfortunately such resistance has not had the support of institutions and organizations that could mediate a strategic approach to scientific knowledge. In this case, the clash between experts' reports and parents' experience reveals the extent of the violence of evidence. Health authorities have described the suffering of girls and parents as "hysterical" because their account does not correspond with the kinds of knowledge that are considered legitimate sources of evidence (see Hanbury, Chap. 8, this volume, about the adverse effects of HPV vaccines in the UK). This clash between experts' evidence and parents' experience shows conflicts generated by the ways in which vaccines are justified as the right tool of care. Hanbury has shown how the suffering of parents and girls related to vaccine injury is not only not recognized as real by health-care providers, but also became a source of distrust and suspicion. In the Colombian case, not just families but entire communities became suspicious. They are then portrayed by the state as ignorant, superstitious and irrational. Evidence defines particular experiences as real and legitimate while others acquire a subordinate ontological status. Parents and girls do not recognize the legitimacy of the experts' accounts. However, it is precisely the resistance to their authority that produces some of the most painful consequences for parents and girls: not accepting medical explanations excludes them from state health-care provision. On the other hand, the lack of a clear answer from the Colombian government and pharmaceutical representatives puts them in a situation of permanent uncertainty regarding their daughters' well-being and health.

Now, in 2016, there are few official references to the Carmen de Bolívar outbreak. Following the results of the experts' commission (which did not find any medical evidence linking the vaccine to the adverse effects), media and politicians have not made any public reference to the outbreak and girls' health. However, many independent blogs have sprung up in Colombia reporting stories of adverse effects and advocating the suspension of HPV vaccination. These voices have had little impact in changing policy. Health authorities have ignored them and have regarded them as expressions of the dangerous and irrational anti-vaccine movement. The Ministry of Health reported that HPV vaccination coverage rate has dropped from 78.5 percent to 20 percent during the last year (*El Tiempo* 2014). In these circumstances, HPV vaccination is not only not cost-effective, but the credibility of the expanded program of immunization has seriously deteriorated.

6 Conclusion

This chapter has presented a fragmented account of the ways in which evidence, sex and drugs intersected each other in the introduction of HPV vaccines in Colombia. Through a sampling of discourses circulating in Colombia, the situatedness of experiences is shown in a global context of circulating drugs and subjectivities. At the same time, close readings serve to avoid presenting the accounts as exotic. Medical and epidemiological imaginaries and representations about cervical cancer have been deeply intertwined with the recognition of social difference. Race, gender and class have been coordinated to identify risk and to produce populations at risk. HPV vaccination and cervical cancer prevention campaigns in Colombia have reproduced these imaginaries in a context in which cervical cancer has become strongly associated with social and economic underdevelopment. These representations are also enacted in the production of epidemiological data and in the technical studies that constitute evidence.

Sex has been used strategically in the production of value of HPV vaccines. These drugs are "sexed" by numbers through the presentation of data and statistics. However, such representation opens up tension in relation to girls as sexualized subjects in a context in which the connections between sex and disease involve an element of stigma. Colombian vaccination campaigns have softened such tensions by highlighting the Colombian "racial democracy" and presenting the vaccine as a policy of inclusion.

However, an outbreak of adverse effects illustrated the complexity of the relationships between sex and drugs and the limitations of policies and evidence in controlling them. This outbreak has shown the consequences of the state paternalism. Policymakers portray parents and the general public as unable to understand the complete set of arguments that support vaccination, as the gap between the calculations of experts and public opinion displays. Once an event such as the outbreak happens, the lack of transparency is visible and the apparent trust in medical and government authority is broken. The connection between sexuality and HPV vaccines has been one of the triggers of debate and social mobilization against the vaccination program. This is one of the relationships that experts tried explicitly to hide. In this context of lack of trust and social mobilization, evidence becomes an act of violence, in which parents' and girls' experience is perceived as unreal for experts and health authorities. The debate about HPV vaccines in Colombia shows the increasing power of evidence in the governance of life and health care, but also its limitations, and raises key questions about the production of evidence and its relation to health governance and legitimacy.

Finally, these stories about the introduction of HPV vaccines in Colombia offer an image of the ways in which drugs are produced and circulate in a globalized world. HPV vaccines are drugs whose fast licensing and global marketing have enabled them to circulate among different locations and national boundaries. In these different locations, HPV vaccines have produced a complex set of relationships with policy infrastructures, political cultures and the material and historical configurations in which they are introduced. The drugs have transformed these contexts, reproducing and localizing some global tensions around sexuality, safety and anticipation. Something similar occurs with EBM, when its techniques and devices of calculation claim to be global, standardized and universal. However, they are appropriated and transformed in relation to government styles and local political cultures. In the case of the introduction of HPV vaccines in Colombia, it has meant a mix between evidence, clientelism and paternalism.

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8

Young Women and the Pharmaceutical Burden of HPV Vaccinations

Ali Hanbury

This chapter explores how young women are positioned as responsible for the health of themselves and their (assumed male) sexual partners through the introduction of the human papillomavirus (HPV) vaccination program. The vaccine has been granted approval for administration to both women and men. Indeed the drug is available for both women and men in the USA and Australia. However, the policy decision within the UK and many other countries including Sweden and Colombia, see Lindén (Chap. 6) and Maldonado (Chap. 7) (both this volume) is for a national vaccination program to be offered to girls and young women only. Therefore, I ask, do young women bear the pharmaceutical burden of HPV vaccination? If so they are made responsible for reducing the transmission, incidence and etiology of the most common viral sexually transmitted infection (STI), the HPV that affects all genders.

As a backdrop, within the UK's HPV vaccination program, both sexing and gendering practices are apparent in many ways. The program

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"sexes" the participants in that those offered the vaccine are those who have been sexed at birth as female through bodily characteristics such as the external genitals. Young people are then further "gendered" through the social segregation of the vaccination program as a result of being socialized in life as girls and young women. The practices I highlight assume that each participant in the program has a uterine cervix, a body part often thought of as being an integral part of being female. The pharmaceutical drug used in the vaccination program is effective against a viral STI that affects the genitals and other areas of the body linked to sexual activities, for example, mouth, anus and pharynx. Therefore being female is not a necessity for receiving the vaccines; young men could equally be recipients of the vaccine but they are not. This chapter therefore explores how and why young women bear the pharmaceutical burden of the HPV vaccine.

My aim for this chapter is to highlight the practices of gendering and sexing through empirical case studies of vaccine injury. I provide space for the stories and accounts of vaccine injury, with little analytical intrusion as a way of appreciating the openness and trust that these families have shown in talking with me. In this approach, I aimed to create an emotionally engaged (Rogers and Ludhra 2012), respectful research relationship that recognizes the intrusion already made into their personal lives through the vaccination program, without further exacerbating potential harm, given that the nature of their experiences has been significantly damaging enough. It was a challenging study, but one which led me to feel a solidarity with these women and their testimonies. Part of this came from rapport through the conversational interchange. But my emotional response also grew from witnessing the iatrogenic effect of the pharmaceutical interventions described to me by the young women and their families. This was strengthened by hearing about the subsequent accusations from health professionals in whom they'd had trust and respect, ostracizing them from the program in which they had previously had faith and optimism that they/their daughters would benefit.

The research materials presented in this chapter were collected as part of my doctoral research during the period February to September 2013. The overall aim of my PhD research was to look at young women's experiences of the HPV vaccinations. All parents and young women in this chapter were contacted via the Sane Vax network,[1] which campaigns for safe, affordable, necessary vaccination. Their core activities and campaigning have been with regard to the vaccine-injury cases following HPV vaccinations. I designed a semi-structured research conversation and carried this out with young women and parents (Somekh and Lewin 2005). I chose semi-structured questions so that I could allow for the unexpected to be created and captured and in order to open up the space for the research conversation to progress according to the interests and experiences of the young women and parents, for them to take the lead. The cases presented here are a selection of the stories I have collected via home interviews, telephone interviews and a focus group. These stories focus on vaccine injury as an empirical fact of the research materials I have gathered. They are part of a wider PhD thesis which, in turn, is part of a broader research project looking at the prescriptive properties of various pharmaceutical products, which produce specific cultural and societal realities and expectations as well as bodily health. The HPV vaccination program prescribes a particular version of femininity onto the lives of young women; they must accept unquestioningly the vaccination and view it as a positive health measure introduced into their lives. Young women will behave in a particularly compliant way and, in turn, their bodies must accept the pharmaceutical drug in a way which is unproblematic. This is yet another way in which the lives of young women are dominated by the ideals of neoliberal expectations of femininity that promote individual freedoms to choose from a very limited set of available options. Of note too is that while HPV has been constructed and critiqued as a privileged vaccine, particularly in national contexts which do not offer it as part of a nationally subsidized vaccination program, issues of race and class did not appear directly in my material—though this is not to say they were not present. For an intersectional analysis of a HPV vaccination program, see Maldonado (Chap. 7, this volume). I did, however, see a discourse around the privilege of choice which problematized the ability to actually make choices; see below.

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[1] Sane Vax is a campaigning network of families and allies affected by vaccine injury. The acronym stands for Safe, Affective, Necessary, Effective Vaccinations. Accessed June 20, 2013, at www.sanevax.org.

1 Appropriate Femininity

Looking at a wider and more recent historical view of youth policy and opportunities, young women's programs are often reported by youth practitioners as being far less resourced than those for young men.[2] One possible exception to this is the targeted work during the period 2000–2010 which was aimed at reducing teenage pregnancy through the Teenage Pregnancy Strategy (Social Exclusion Unit 1999; Hanbury 2015), as well as recent "panics" regarding sexualization of young women and the focus on long-acting, reversible contraception methods which all view women as at risk or deficient in their own capabilities to manage their fertility and conception (Hanbury and Eastham 2015).

It is just such strategies that see young women occupying a precarious position, often thought of as a transitional period of adolescence or "youth." In everyday media portrayals they are deemed to be troublesome or vulnerable, and thus in need of intervention or protection. Accessing knowledge, particularly sexual knowledge, poses a difficulty during these years, especially when such knowledge transgresses the heterosexual identities that are so frequently promoted throughout childhood, adolescence and into adult life (Curran et al. 2009; McRobbie 2009). The will and desire to protect the vulnerability and innocence of childhood and youth can often result in the re-articulation and recycling of unhelpful (mis) information regarding, for example, conception, pregnancy and childbirth, along with the eradication of the recognition, value and worth placed upon women's labor in them. These are processes with such clinical intervention and interest that the labor-intensive hard work of women in carrying them out is often unrecognized as a result of the clinical advancements that are celebrated instead.

In Jackson et al.'s (2010) collection *Girls and Education 3–16: Continuing Concerns, New Agendas*, a wealth of empirical work is brought together that highlights "the problematic position of girls and young women in the education system; caught between being represented in large-scale data sets as achieving higher G.C.S.E. results than boys and young men which has resulted in a "poor boy discourse" and being sexually and

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[2] Accessed October 10, 2016, at www.feministwebs.com.

racially "Othered"" (Jackson et al. 2010). Such assertions prove important for my project, as school and the education system is where young people will spend a significant period of their "youthful" lives in the company of peers and with the potential/opportunity to engage in myriad intimate and/or sexual relationships. It is not only in this setting that young women explore, play out and negotiate their sexual selves but they are also "gendered" through being encouraged and supported to look to the future as women and potential mothers, to anticipate events and adopt preventative behaviors now for the benefit of their own lives and those of their imagined future partners and children. This gendering occurs through careers fairs, the necessity to choose subject options during high school and through the added insertion of the new HPV vaccination which tells a story of risk to health, and which I suggest promotes young women's responsibility for future healthy relationships, safer sexual practices and being cancer free.

Feminists have long been critical of numerous ways in which women's bodies are sites of invasion, surveillance and, through various methods, control (Ehrenreich and English 1973, 1978). Janet Batsleer suggests that dominant versions of successful femininity center on bodily practices such as removing hair, fluids, fat and so on and of restricting things such as bodily smell and movement (Batsleer 2013). Similarly, yet some years earlier, Susan Bordo asserted, "Through the exacting and normalizing disciplines of diet, makeup, and dress—central organizing principles of time and space in the day of many women—we are rendered less socially oriented and more centripetally focused on self-modification" (Bordo 1993: 166).

Inspired by such scholarship it is my suggestion that the HPV vaccination program reifies the problematic anxieties about young women's sexuality being seen as at risk of exploitation, early pregnancy and STIs and (re)produces an "appropriate femininity" which counters these. The HPV vaccination program views young women as at risk and vulnerable to the future possibility of cervical cancer and genital warts. But as I detail in the following pages the accounts of a particular group of young women regarding their experiences of the vaccination, I will argue that various surveying practices of the program serve to align the compliance of young women with a specific version of femininity conducive to the vaccination program, and encourage acceptance and obedience.[3] Without such compliance, the vaccination program, which has been absorbed into the workloads of school health advisors and their staffing resource and capacity, would not be possible. If too many young women refused the vaccination, this would reduce the efficacy and justification for the existence of the HPV vaccine itself, and reduce the chances of the "herd" being protected.

However, the engagement of the young women that the HPV vaccination and program relies upon could be undermined by an increasingly audible post-feminist discourse of young women's opportunity, choice and independence. Yet this neoliberal discourse of individual choice does not reflect upon the options from which one can choose. Feminist scholar Imogen Tyler suggests that neoliberalism is "an ideology which aimed to restore and consolidate class power, under the veil of rhetoric of individualism, choice, freedom, mobility and border security" (Tyler 2013: 177). Tyler's case studies of activism and marginal subjects/citizens provide alarming instances of the failings of neoliberalism to secure the promised individual prosperity for all who try in accordance with society's conventional markers of success, given the weighty legislative and attitudinal odds stacked against them.

In a similar vein, Angela McRobbie summarizes the position of feminism within this discourse of the neoliberal ideals of freedom and choice, and the effects this has on young women's abilities to achieve sexual recognition:

> By means of the tropes of freedom and choice which are now inextricably connected with the category of young women, feminism is decisively aged and made to seem redundant. Feminism is cast into the shadows, where at best it can expect to have some afterlife, where it might be regarded ambivalently by those young women who must, in more public venues, stake a distance from it, for the sake of social and sexual recognition. (McRobbie 2009: 11)

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[3] Surveying practices include the telephoning of parents to gain consent for vaccinations, the reporting and online availability of annual uptake rates and the vaccination completion/compliance targets for each geographical area.

McRobbie reminds us that a neoliberal rhetoric of individual choice has replaced a more collective solidarity of feminist action and equality. By focusing on the (fallacy of) freedom and choice, young women are cast as autonomous subjects with access to the means and opportunities through which to make agential decisions.

Choosing to accept the HPV vaccination for their daughters, parents (often mothers) are guided through the process of decision making by a convincing, yet limited, narrative account of biomedicine which promotes common-sense sentimentality regarding the "fight against cancer" that all women should be a part of if they are to be appropriately feminine in their life choices.[4] For the young women and families I introduce in this chapter, the practices within the vaccination program position young women as responsible and appropriately feminine, and this position is challenged as a result of vaccine injury through experiencing life-limiting side effects. Furthermore the empirical cases of vaccine injury not only highlight the assumptions of appropriate femininity but also identify the sexing and gendering practices that precede these.

2 Case Studies of Vaccine Injury

Through collating information, Sane Vax's secretary puts parents and young women in contact with one another to create and share collective knowledge and information which may help with diagnoses and treatment. This is done mainly via email and Facebook, after which some parents talk over the telephone or via video. One of the overarching themes that came from the cases I will present is the psychological diagnoses which medical professionals have tended toward in response to the young women's changing and contestable symptoms and their parents' challenges to the safety of the HPV vaccine.

Broadly speaking, to comply with socially desirable and expected behavior at various stages of the life course, accepting vaccination is

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[4] See breast cancer activism's critique of the "Pink Ribbons" merchandise including the film from Pink Ribbons Inc. (2011), *Capitalizing on Hope*, Director: Lea Pool; and Barbara Ehrenreich's (2009) book *Smile or Die: How Positive Thinking Fooled America and the World*.

a way of performing as a rational, informed and reasonable woman in good health. The opposite is a range of undesirable behaviors that include self-administration of illicit drugs, the use of prescription drugs against prescribed orders or those that have been prescribed for use by others or defaulting/refusal to comply and accept vaccines or other drugs. And I assert that an extension of these undesirable behaviors includes not only the experience of side effects but the practices of challenging the authority and efficacy of the medical profession as a vaccine-injured subject.

The HPV vaccination program is free and voluntary (despite national targets), offered to all young women within a certain age range. Thereby the UK government is promoted as displaying positive caring practices for its citizens, a state that invests its resources and finances into a national, free vaccination program. However, as this is a gender-specific vaccination program, I utilize the five cases below to argue that the pharmaceutical burden is carried by young women despite HPV and the vaccine being gender-neutral in composition. With an uptake target of 90 percent for the HPV vaccine and blanket administration practices through the compulsory schooling setting, I bring various concerns into scrutiny. These cases of vaccine injury provide a view of the HPV vaccination program as being both limited and complex in its administrative practices, as well as being problematically paternalistic in its interventionist approach to young women's lives (Dubriwny 2012).

2.1 Jackie and Milly: Medical Exclusion

Around the kitchen table, with plates of sandwiches, salad, cakes and coffee, and with a grumpy old Labrador growling gently at the stranger at their table, Milly and Jackie shared their stories. Here Jackie talks about Milly's symptoms in relation to other young women with whose parents she has had contact or knowledge of:

Jackie: And they were very similar, seemed similar people, similar types of people, and I spoke to her a few times when Milly was first started to be diagnosed, and her [Karen] daughter's gone through exactly the same pattern as Milly. She goes to an ME clinic and the rest of it, but she's two years ahead of Milly and I can remember having a conversation with her mum and her mum said, "Oh and Rosie suffers with this and her joints" and I was going "Oh yes, Milly has problems with her joints" and so on. She says, "Does Milly have problems with her ribs? It drives her mad, her ribs just hurt." I went "Oh no, she's never complained of that," and I made a point of not telling Milly because I thought, I don't want to plant information in her head, so all these things I kept to myself. And then lo and behold the week after, "Oh my ribs," and this happens so often where …

Milly: lump in my throat …

Jackie: Yes, Karen would say, "Oh Rosie has problems with her lymph glands and things," you know I'd think, "Oh no Milly hasn't, we're not suffering with that." And then lo and behold she'd have this big lymph, oh it was under your arm wasn't it, big lymph.

Milly: And I couldn't lift my arm up.

The parents are a significant part of their daughters' experiences of ill-health. They provide care for them; they advocate for their health care and treatment, undertake time-consuming research and are also involved in campaigning and in media stories. The parents feel a responsibility not only to their own daughter and family but also to the wider community of vaccine-injured young women.

During the interview I asked Milly how many doctors she had been to during the past two years and what their responses had been like. She told me that she'd been to "countless. I've been like a pin cushion the amount of blood tests and things I've had" and that from those responses they have been "75% bad." An example of a "bad" clinical response was following the sabbatical of her pediatrician. She was then referred to another one, Dr. Jones.

Jackie: And we transferred to Dr. Jones, the other pediatrician, who won't talk about the vaccine, he doesn't want to know.

Milly: He won't entertain it.

Jackie: He doesn't want to know about it, he refuses to …

Milly: He thinks you're just grasping at straws.

This assessment of Dr. Jones was made following an appointment that Milly and Jackie attended, where Jackie was excluded from the consultation. They recounted the story in tandem during our research conversation. They told me of how Dr. Jones made Jackie sit at the back of the consultation room and sat with his back toward her while he asked Milly to tell him about her symptoms. When Jackie attempted to move her chair closer to her daughter, initially surmising that the chair had been placed at the back of the room as it was seldom needed, Dr. Jones reportedly said:

Milly: “No, no, that’s your seat over there Mrs. R, I want Milly to sit here” and then like, I wouldn’t know what to say or I’d forget because my memory’s so bad and I look at my mum at the other side of the room and he’ll go, “no, no, look at me, I want you to tell me, not your mum.”
Jackie: Yes he completely cut me out. Milly thought it was hilarious.
[BOTH LAUGHING]
Milly: [You were] trying to butt in and he’s going “no, no no.”
Jackie: He really put me in my place.

Throughout the process of accessing medical professionals Jackie and Milly have felt excluded and not taken seriously. Despite their laughing, they are upset and frustrated with this, when telling this story. Milly has also made it clear that she requires Jackie’s support due to her “brain fog” and memory loss. However, it is important to consider what could have been motivating Dr. Jones to act in such a way and to exclude Jackie from the consultation with her daughter. Milly and Jackie have their own theory as to why this is:

Milly: I think he thinks that you’re an overanxious mother.
Jackie: Yes, from a lot of the parents that I’ve spoken to, not just the vaccine related ones but the ME[5] girls with ME that’s unrelated to the vaccine. If you push and question doctors too much, you

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[5] Myalgic encephalopathy (ME); it can involve severe fatigue, painful muscles and joints, sleep disturbance, gastric problems, poor memory and poor concentration. This acronym is often used interchangeably with CFS (chronic fatigue syndrome).

> get labeled with either being overanxious or in the extreme case Munchausen's by proxy.[6]

Being labeled and suspected of harming your child (as in the risk of being assessed for Munchausen's by proxy) is an experience a number of parents have shared. This experience of blame and shame goes beyond the rudeness when a doctor places a chair at the back of the room, the dismissal of side effects and the refusal to acknowledge or accept that the HPV vaccine has harmed the young women.

2.2 Andrew, Linda and Gemma: Fabricated or Induced Illness (Munchausen's by Proxy)

In April 2013, Andrew and Linda invited me to their home to interview them about their daughter's vaccine injury. They had originally decided against the HPV vaccination for Gemma as she had suffered side effects following the measles-mumps-rubella (MMR) vaccination as a small child. However, according to Andrew, "The school nurse convinced mum that this vaccine wasn't like MMR that it was quite safe and persuaded mum to sign the consent form." Gemma received the vaccines between October 2010 and May 2011, and when Andrew and Linda looked back at her medical records, they saw that her symptoms had started in December 2010 but had attributed them to flu. They now believe this was the onset of her vaccine-related illnesses. What followed were months of ill-health, possible diagnoses and inconclusive tests:

> [Gemma had] extreme exhaustion, feeling very cold, tired, abdominal pains, severe headaches. The GP thought that Gemma had glandular fever but all tests were negative, did lots of tests. She was admitted to hospital and attended hospital on several occasions. Gemma had a huge number of blood tests, scans, x-rays et cetera, but all tests were negative. On August

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[6] Fabricated or induced illness (FII) is a rare form of child abuse. It occurs when someone who is caring for a child, usually the child's biological mother, fakes or deliberately causes symptoms of illness in the child. FII is also known as Munchausen syndrome by proxy. Accessed October 7, 2013, at www.nhs.uk.

> 10, Gemma collapsed and was unable to walk without support. She was admitted to hospital again with suspect brain tumor.

Following brain scans, a brain tumor was ruled out and the consultant they saw first agreed "in writing to the GP that 'it is quite likely it'll turn out to be the HPV vaccine'." Despite this, subsequent consultants at further hospital visits disagreed when Linda brought up the vaccine as a possible causal factor. During July and August 2011 Gemma was sleeping for between 20 and 23 hours per day. Gemma missed school for the entirety of academic year 9 (third year of high school, ages 13–14 years), as in "September Gemma couldn't open her eyes and lost her voice and for the next 13 weeks slept constantly. She stirred to press a bell for medication for the constant pain, we spoon fed her liquidized food but she was never fully conscious."

Andrew and Linda became aware that they had been investigated for Munchausen's by proxy, or fabricated or induced illness (FII), after an unsuccessful claim was made to the Vaccine Damage Payment Unit. Following this outcome they requested the information upon which the decision was based, and the private provider carrying out the assessment on behalf of the Department for Work and Pensions released the medical records to the family which included this investigation. Linda felt clear that the reason for her and her partner being investigated in this way was a health-care professional's refusal to accept that the HPV vaccine had caused Gemma's ill-health. Here Linda focuses on the notion of the role of supporting the claims or suspicions of the medical professionals:

> Once somebody mentions FII or Munchausen's by proxy, it takes a whole different new route. But that should never have gone on for as long as it did, never ever, because, you know, where's their evidence? They haven't got any, the only evidence they have is, they don't want to believe it's the vaccine, so if it's not the vaccine, what else could it be and they don't have an answer, so the obvious answer is to point the finger at the parents.

Toward the end of the interview with Andrew and Linda, Gemma came into the room. I had noticed her in the adjoining room, sleepily wrapped in a blanket, with a small dog nestled into her. Gemma was visibly very tired and her body seemed frail and sickly. Her voice was low, and she spoke slowly and without many specifics or much clarity. Gemma told me that she didn't remember the three months when she was sleeping for most of the days. Linda recalled her being surprised to wake up in mid-December to see the Christmas tree had been put up and decorated. Since starting to wake more, Gemma now receives Skype consultations from a homeopath. I asked her what she thought of the vaccine, to which she replied:

> I don't even think of vaccines as being harmful, it's just it wasn't right for me and I don't have any problem with medication, but if I can get it through [the homeopath] it doesn't have any side effects, I'd rather go that route.

These families are challenging the medical professionals and pharmaceutical companies as a result of side effects. They are not anti-vaccination campaigners who have prior critiques and hold opposition to vaccines and other prescribed drugs. This position adds to their disbelief and incredulity when they seek recognition of vaccine injury. They have previously had faith in and have invested in medicine, and they are now disappointed that the system they believed in is failing them.

2.3 Julie and Marilyn: Contraindications to Vaccination and Guillain-Barré Syndrome

In 2013 I organized a focus group in the southeast of England. There were seven adults who attended, representing five vaccine-injured young women. Following this focus group, I left the church hall where it was carried out, exchanged thanks, my gratitude and walked toward the train station. Before crossing the street I began to cry at the enormity of the stories that had been shared with me. The pain, the dismay and the utter dejection felt by these families led me to experiencing a four-day episode of “vicarious trauma” (McNamara 2009). The accounts that follow provide an insight into the experiences that were shared with me.

My main contact for the focus group was a woman named Julie. She recounted the onset of symptoms for her daughter like this:

> Her eyes were twitching, her legs were giving out. Her eyes were twitching, she couldn't sleep, dizziness. You've heard it all before. I even rushed her down to A+E once because she couldn't feel her leg. She cries out "I can't feel it, I can't feel it" and that was how Guillain-Barré's[7] started when she was three years old, it started in the legs. And back then the doctor's thought, 'cause I called the doctor out on it, he tried to make her stand up and she collapsed. She was only three years old. I heard him on the phone: "I think this child's legs are broken." And he had her rushed down the hospital. And we found out she had Guillain-Barré syndrome. So when she was doing that Saturday night I panicked. Sunday morning I got up and brought her down to A+E […] I mean we wonder if giving her vaccines gave her Guillain-Barré?

On the Saturday in question Julie's daughter Marilyn was experiencing an episode of extreme leg pain. Once at A+E the doctors wanted to take blood for tests. Marilyn began to cry and Julie explained that she has Asperger's syndrome, suffers from some anxiety and is scared of needles. Marilyn explained that the doctor then attributed Marilyn's tingling, twitching and achy limbs to her anxiety as a manifestation of her Asperger's syndrome. Despite Julie's arguments to the contrary they both left the hospital in tears feeling let down by the situation. At the time of the focus group Marilyn and Julie were still awaiting further tests but were also cautious that her medical notes would concentrate on her Asperger's syndrome diagnosis being the root cause of her anxiety and bodily symptoms.

Following self-directed research into symptoms and possible vaccination side effects, Julie felt annoyed that she had not looked more into the new HPV vaccine and told us:

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[7] Guillain-Barré syndrome is a rare and serious condition of the peripheral nervous system. It occurs when the body's immune system attacks part of the nervous system (http://www.nhs.uk/conditions/Guillain-Barre-syndrome/Pages/Introduction.aspx).

> I could kick myself 'cos I never let my kids have the MMR because of all the controversy over it. Because this [HPV vaccine] was quite new, obviously I hadn't heard of any of this. If I'd have done my research there's no way she would have had it because I wouldn't give my children the MMR.

This along with her rhetorical question in the opening quote I have included from her which asks "we wonder if giving her vaccines gave her Guillain-Barré?" has led Julie to reflect upon the information and consent practices that play out during the vaccination program's administration:

> We got one letter […] it didn't really explain much at all. You signed the consent form and [after the first injection] Marilyn was given, she didn't bring it home unfortunately, but she would have been given a leaflet out of the box [Patient Information Leaflet] after the vaccine about all the side effects […] You can't give a child an injection and then give you the information afterwards.

Following a report via the Medicines & Healthcare products Regulatory Agency using the Yellow Card system whereby Julie reported a full list of Marilyn's symptoms and belief that they were side effects from the HPV vaccination, the reply she received stated that the Patient Information Leaflet (PIL) recognized and listed that these side effects were a possibility. But the key critique here is that Julie believes that the information regarding side effects should not be given after the first injection but prior to the decision being made about whether or not to accept it. In the PIL it states that you should inform your doctor if you/your child has a weakened immune system prior to vaccinating. Many parents have done this but receive responses that doubt the vaccine's causal role. The PIL also states under Section 4 Possible Side Effects: "As with other vaccines, side effects that have been reported during general use include: swollen glands, Guillain-Barre Syndrome, dizziness, vomiting, joint pain, aching muscles … " (Sanofi Pasteur MSD 2012). Had Julie seen this leaflet prior to making the decision on whether to vaccinate, she would not have consented for Marilyn to receive the vaccines.

2.4 Vicky and Pollyanna: Mental Health Services and Self-Harm Diagnosis

At meetings of the focus group Vicky waited patiently for her turn to speak. She would interject when other parents spoke of their daughters' symptoms and experiences, often nodding and providing verbal cues that indicated the similarities with Pollyanna's case. Vicky brought with her a display folder of many letters, health records and photographs of Pollyanna's bodily symptoms. Pollyanna was 12 when she had the HPV vaccinations with Cervarix, starting in December 2009. Following her first vaccine, Pollyanna felt achy and had flu-like symptoms. Following her second vaccine in January 2010 Pollyanna was feeling increasingly worse with general fatigue and ill-health which carried on for some weeks. In April, she returned from school with skin welts as described by Vicky:

> It looked like an insect bite quite honestly, it was red around the outside, white in the middle and it looked like lots of little bumps inside. It was like a, I don't know, some kind of bite or something, and we watched it turn into tiny, tiny, tiny little blisters and then you watched it, it was like watching mercury. We watched the tiny blisters all sort of join up and make one huge big blister, then it popped and all this yellow liquid sort of came out, and then it just started ulcerating and then within a couple of hours she had another one on her other arm, so I took her to A+E 'cos the doctor was shut at that point.

Pollyanna was diagnosed with impetigo and told to remain off school as it is a highly contagious bacterial infection. During this absence Pollyanna missed the third HPV vaccination but Vicky had told her daughter that she didn't want her to have it as "my mum had sort of said to me, 'do you think it could be anything to do with the vaccination?' and I went 'ooh I don't know, maybe I'll have to have a look into it'." When the welts continued to develop, further diagnostic tests ruled out any bacterial cause and thus it could not have been impetigo. Following months of ill-health and various doctors' appointments, in November 2010 Pollyanna rang Vicky

> in tears and said that they'd forced her to have it [third vaccine] even though she'd said "mummy had said" she wasn't allowed to have it. And they said, "it's too late because you know your mum's signed the consent form," so I'd signed the consent form [previously] so she had it done. And then it just got worse and worse and worse.

Following many referrals to different health professionals, Pollyanna then had an appointment with a dermatologist who claimed she knew what was happening, that is, that Pollyanna was self-harming.

> My mum […] she said, "she obviously knows what she's talking about because she works at Great Ormond Street and she's been a dermatologist for 19 years" and I went, "well that's great mum" I said "but you know, I don't think she's right, I'm Pollyanna's mum."

It was at this juncture in the story that Vicky clearly displays a more agentic practice in the patient–doctor exchange. The hierarchy of power has been seized and Vicky is now taking back the expertise and trust over the knowledge of her daughter; she no longer trusts the doctor; instead she is staking her claim to knowing Pollyanna (and her symptoms) best. Vicky shared that Pollyanna "wouldn't [harm herself]. She's a wimp, she's a wimp when it comes to pain, you know, and she gets a paper-cut and she thinks she needs stitches and reconstructive surgery, she's awful." Vicky refused the suggested referral and assessment to the Child and Adolescent Mental Health Service (CAMHS). Both the "diagnosis" of self-harm and the refusal were noted on Pollyanna's medical records despite further assessments which suggested an autoimmune disorder being the cause of these symptoms, and then subsequent clear blood tests. The tests, diagnoses and assertions by various health professionals differ and create the illnesses and symptoms as problematic for being able to understand and fit them into a neat category for aiding or curing. Despite the various and contradictory diagnoses, Vicky feels that the suggestion of self-harm will have a lasting impact on how the situation is viewed by any new health professionals. She told us:

> it's [self-harm] there on her records, everywhere and every letter of referral, it's you know, it's wedged in there somewhere, you know, I'm deluded, I'm

> a troublemaker, I'm deluded because my daughter is effectively pulling the wool over my eyes.

Vicky feels that despite the differing opinions and test results, the psychiatric assessment and the refusal of the CAMHS assessment will negatively affect the way in which she is viewed and her daughter treated. As a result, several parents are now being more strategic in their interactions with health professionals and are cautious about the psychiatric diagnoses and suspicions that they may be risking.

2.5 Mark and Stephanie: Pervasive or Persistent Refusal Syndrome and Psychiatric Sectioning

In the focus group, Mark told me about the experiences of his daughter Stephanie. Mark and his wife first heard about the vaccine through school, after which they asked a good friend of theirs, who is a nurse, what her thoughts of it were. She stated that she couldn't see any problems with it as it was not a live vaccine. They signed the consent form and Stephanie received her first vaccine in 2008. Stephanie's side effects started within one week of her first vaccine with pain in her hands which soon began "shooting" around her body. Mark stated that, upon taking Stephanie to the GP who asked "Is there anything different that she's been having?" they said, "The only thing is the vaccination" to which the GP reportedly replied, "Oh the vaccination's safe, it's not that," and subsequently Stephanie received both her second and third HPV vaccines.

Mark reported that Stephanie's pains became progressively worse following each vaccine and the joints in her knees and hips became extremely painful, so much so that she needed crutches to aid her walking and was receiving physiotherapy. Mark told me how he and his wife Kim had continued to highlight the vaccine when asked by doctors, but received reassurances of its safety. During an appointment with a rheumatologist Mark stated:

> He just took one look [at Stephanie], he said "what's she been doing?," [I replied] "Vaccination," "What Cervarix?," "Yeah" and he went "Why on

> earth did you let her have the third injection?" [and I said] "Because everyone said the vaccination is safe."

Of gravest concern to many of the parents with vaccine-injured daughters is the fear of what they see as unnecessary psychiatric intervention. Following the action of Stephanie's parents to try to receive a diagnosis, treatment and recognition of causality, Stephanie was sectioned to a psychiatric unit and subsequently spent almost two years at this facility diagnosed with pervasive or persistent refusal syndrome.[8] Mark told me during the focus group that Stephanie had used crutches and a wheelchair at times but, despite high doses of painkillers, still experiences excruciating pain which means she does not like her legs and joints being touched and refused palpation during clinical consultations. Mark stated that he believes this led to him and his wife being suspected of physical abuse and Stephanie's brother questioned about potential familial abuse.

Mark believes that Stephanie received incorrect medical advice, which was to "push and push" so that Stephanie remained active. Mark now believes this advice to have had a detrimental impact upon his daughter's health. Following five years of ongoing ill-health Mark states that Stephanie also believes that she has been treated unkindly and unfairly by many physicians. After repeating her story tens of times and cataloging her symptoms, Mark told me that she "got fed up of telling the same people the same things over and over and over again. She said, 'I'm not talking to you any more, you don't listen to me, why on earth should I talk to you?'" This, along with a lack of improvement that was expected following the prescription of strong medication, led to Stephanie's diagnosis with pervasive or persistent refusal syndrome.

Diagnosing is something that Mark and the other parents felt that clinicians prioritize. Once they diagnose they don't then look into other avenues or take any other things into account. Mark said, "they fit you into a box and once you've got in that box, you're there and that is it." The parents were frustrated by what they see as the main aim of the clini-

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[8] A rare psychiatric disorder characterized by refusal to eat, drink or engage in self-care and a resistance to treatment first documented in 1991. Since 2011 it no longer appears in the psychiatric diagnostic manual.

cian as being to make a diagnosis, and once this has been achieved it is difficult to look or act beyond that.

3 The Risks and Benefits of Health Advocacy

These cases highlight how the parents are deemed to be, and take on the role of being, responsible for their daughters' health and advocacy. They are also in good enough health to fight on behalf of their daughters. These parents are fully involved and embroiled in the experiences of their daughters and are the health advocates of/for them. Their fight is not only for the recognition that their daughters are ill but for doctors to believe that the HPV vaccine has caused this ill-health. This would require clinicians, health professionals and institutions to accept that their industry and intervention could cause significant life-limiting illness. The embodied knowledge and expertise of these parents and young women appears to be in conflict with the "expert" knowledge of clinicians.

Feeling outside of the mainstream experiences of vaccination has been difficult for Milly and Jackie; Andrew, Linda and Gemma; Vicky and Pollyanna; Julie and Marilyn; Mark and Stephanie and other vaccine-injured young women and their families. To counter the authoritative claims of the UK and Europe's largest and most powerful medical organizations, committees and pharmaceutical companies or to challenge their authoritative knowledge has put them at risk of being labeled deviant or mad.[9]

Worry about this was highlighted in my interviews, for example, when Jackie said, "If you push and question doctors too much, you get labeled with either being overanxious or in the extreme case Munchausen's by proxy." The process of not being believed and the continued challenging of the medical profession can result in being assessed for Munchausen's by proxy/FII, child abuse, being labeled as "mad" and even feeling mad.

Many of these families are not anti-vaccination in their views or political positioning; rather, they have found themselves in opposition to the vaccination program as a result of side effects, which is not

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[9] See Maines (1999) and Showalter (1997) for a history or "hystories" of women as hysterical.

unusual. As Bell notes, "[M]any embodied health movement activists become involved in response to a direct experience of illness" (Bell 2009: 5). Despite challenging medical professionals and the vaccination, these parents and young women are looking to the medical profession for a response and a subsequent "cure" or treatment of the illnesses presented. However, these parents, or vicarious embodied health activists, are clear that some of the practices of the HPV vaccination program are to be questioned and should be changed. For example, Vicky signed the consent form in December 2009 for Pollyanna to receive three HPV vaccinations. Following her ill-health into 2010, Vicky had told the school to hold off giving her the third injection; yet in November, almost a full year later, the nurses used the same signed consent form to vaccinate Pollyanna despite her verbal indication that her mother did not want her to have it.

Dubriwny's (2012) notion of the activist-feminist approach to health care is useful to note here. She suggests that those engaged with healthcare decisions as patients or consumers of medicine are invested and engaged in their own lives and experiences of health and illness. As such they play an active part in the prescriptive requirements of particular medicines. The young women have to play the role required of them in order for the vaccine to work. That role includes accepting the vaccine without issue.

4 Gendering Practices as Evidenced Through Cases of Vaccine Injury

These young women and their parents initially behaved in the way that was expected of them by the HPV vaccination program and all of its influential stakeholders. Their divergence from the success story of HPV began when things then went wrong. My research tells a story about side effects that occur, and when they do, they occur with traumatic and debilitating effects, and not just physically. These young women are seen as "mad," as self-harming, as persistently refusing to cooperate and in need of psychiatric assessment and involvement. Their parents are seen as hysterical, potentially abusive and as "troublemakers" who are disbelieved when they highlight the vaccine as causal to their daughters' ill-health. The work carried out to assert that their daughters are not in need of psychiatric services is demonstrative of their firm belief that the cause of their daughters' illness is the HPV vaccination.

The process of consent giving is one which has been highlighted as a significant cause for concern and review by these parents. As seen in the empirical accounts above, the information upon which consent has been given was limited and, in hindsight, consent would not have been given by some parents if the full list of potential side effects was known in advance. Furthermore, Vicky, who subsequently withdrew consent verbally following the onset of her daughter's side effects, had her wishes ignored when her daughter was then vaccinated with the third of three vaccines. The HPV vaccination program is set up to stave off any potential decliners, and all of the information and public health materials provided through the "official" channels are written in ways which promote acceptance. Despite a more full and balanced account of the infection and the vaccine not being provided, young women and their parents are seen as unstable and hysterical, and thus unable to make the rational decisions that would have been based upon more detailed information. As the program is geared toward meeting a high acceptance target, consent is "pushed" in a particular direction and the choice that these young women and their parents have is limited. That limited choice is one which is often made under the burdensome risk of being seen as an irrational or unreasonably emotionally cautious woman.

5 The Fallacy of Choice

Choice is a concept that is inextricably linked to the notion of post-feminist neoliberal womanhood. Analysis of the commercial and non-commercial discourses surrounding the HPV vaccine in the USA leads Dubriwny (2012) to suggest that choice is available only to young women who are privileged with regard to their class and racial position. She also argues that the term "empowerment" is limited to young women's ability to consume various health and lifestyle practices, such as vaccination.

In the UK, context decision making regarding whether or not to vaccinate, particularly with new and less established vaccines, has largely been presented to parents as a balance or choice that involves weighing up the risks and benefits; how likely is it that their child will experience serious side effects versus the severity of health problems they will avoid by being vaccinated? If it is believed by parents that the benefits and risk reduction of developing cervical cancer is greater than the likelihood of possible side effects, then vaccination is generally accepted. This argument, however, is one which Pru Hobson-West, a social scientist working on trust, ethics and public understanding of science, problematizes. Hobson-West's work draws upon literatures on decision making in relation to vaccines. Her work concerning organized resistance to the MMR[10] combined vaccination controversy troubles this "risk-benefit dichotomy" and introduces alternative framings of the decision-making process (Hobson-West 2007).

The National Health Service's UK website, NHS Choices, with its strapline "Your health, your choices," states that the HPV vaccine is "offered" as part of a childhood immunization schedule. This then presents "facts," information and statistics about cervical cancer and genital warts, and promotes the HPV vaccination. Toward the very end of the web page about the vaccine it encourages site visitors to "Now, read why it's so important for 12–13-year-old girls to receive the HPV vaccination."[11] Rather than there being a choice between vaccinating or not, the decision is directed firmly and positively toward vaccination. This renders the possibility of choosing not to vaccinate as an unreasonable choice or as being "deviant," noncompliant and/or unfeminine.

However, analysis from the USA suggests that choosing the HPV vaccine involves a very particular and limited acceptance of the potential of the vaccine, that is, the pervasive biomedical discourse of reduced risk

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[10] MMR (measles-mumps-rubella) is a combined vaccine that is usually given in childhood in two doses. The controversy was sparked when a paper was published in the medical journal *The Lancet* in 1998 by surgeon and medical researcher Dr. Andrew Wakefield. This paper claimed that the MMR vaccines were associated with autism and bowel diseases in some children. For more on this see Hobson-West (2007).

[11] Accessed October 7, 2013, at www.nhs.uk/conditions/vaccinations/pages/hpv-human-papillomavirus-vaccine.aspx.

and better health. In their chapter “Re-Presenting Choice: Tune in HPV,” Giovanna Chesler and Bree Kessler use their interest and experience in media and gender to critique the Gardasil “One Less” campaign in the USA, which uses the mantra “I chose.”[12] They state that choosing to accept the HPV vaccine Gardasil based upon the dominant messages and positive promotion of the vaccine “involves choosing to agree to a limited understanding of human papillomavirus” (Wailoo et al. 2010: 146). This point has been highlighted by parents, as they did not have full detailed information before consent was given and therefore their understanding of its effects was limited. The choices presented in both the UK’s NHS Choices webpage and the USA’s Gardasil “One Less” campaign are both heavily geared toward vaccine acceptance.

During my work with the focus group, Julie gave me a letter which demonstrates Chesler and Kessler’s argument of accepting the limited understanding of the vaccine. The letter came from the Immunisation Team at the school attended by her daughter and opens with bold text: “**Beating cervical cancer**” and later “**This letter is to offer your daughter a vaccine to protect her against cervical cancer later in life**” which again appears in bold type. Yet research suggests cervical cancer is a rare form of female cancer in developed and resource-rich countries such as the UK. The letter states that the vaccine is “very safe and very effective” and, after providing the three dates of the doses to be given to her daughter, the letter then suggests that “It would be most helpful if on the day of immunisation your child could wear a loose fitting garment or short-sleeved shirt and have had breakfast.” The letter thus far creates a case for the HPV vaccine which firmly centers the issue as one of beating cervical cancer and which presumes compliance both with the discursive framing of HPV-cancer prevention and with the practicalities of delivering vaccination.

By providing instructions on how the young women should dress prior to the vaccines, the letter assumes compliance and consent even before the request for parents to “sign the form if you are in agreement for your child to receive this immunisation.” This is immediately followed by

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[12] See Tasha N. Dubriwny’s (2012) book *The Vulnerable Empowered Woman* and Elena Conis’s (2015) book *Vaccine Nation: America’s Changing Relationship with Immunization*.

what can only be read as a warning statement: "**Please note that a young person can consent to an immunisation if they are deemed competent to do so**." Finally the letter ends with the sentence: "By having the HPV vaccine your daughter *will be* protecting herself and others against a very serious disease" (emphasis added). This marks the vaccine as unquestionably efficacious and also assumes the young women to be as successfully feminine in the role of a conduit to good health between the vaccine and her future sexual partner/s. This letter also firmly situates her parents as responsible for consenting to the vaccine, for providing breakfast and for ensuring their daughter dresses appropriately on the dates of the vaccines. These assertions powerfully assume the position of good and responsible women who will act in a way which is conducive to the acceptance and success of the vaccination program; thus these assertions further act to gender the young women and mothers.

Of significance here is McRobbie's critique of the post-feminist position that feminism and feminist concerns should be banished to the realms of history because they lack contemporary relevance for women. Instead McRobbie argues that feminism continues to be a necessary lens through which to critique the offers made to young women in the contemporary UK in the guise of providing freedom of choice and control over one's own body. As Valerie Hey suggests, we must respect "the autonomy of girls' and young women's social relations while simultaneously providing resources to think with and against their limits [and] avoid[ing] the perhaps too easy temptation to give in to our own version of feminist melancholia" (Hey 2010: 219). For this assertion I argue that the young women and their parents are capable of and willing to engage in a decision-making process which involves greater considerations of more detailed and open information. The standardized nature of the pharmaceutical products, and also of the administration processes by which vaccinations are delivered, operates on large-scale epidemiological data sets and the notion of the ideal body and idealized conditions of delivery. In addition, the HPV vaccine has been administered based upon general claims which assume cervical cancer is a future woman's disease being "beaten" in the present if she will only make the right choice to vaccinate. However, these families' experiences highlight that in practice this scale view does not help or support young women and can exacerbate their difficult and traumatic situation. The gendering assumptions made here center on the ways in which women are being typecast as being onside with the war against cancer and thus invested in the pharmaceutical-as-savior figure.

6 Conclusion: The Impossibility of Appropriate Femininity

There are several burdens placed upon young women, as the accounts above show. Young women's bodies are taking on the addition of yet another pharmaceutical product as part of a new prescriptive vaccination program in which they are encouraged to participate. As of September 2014 the vaccination program was reduced from three injections to two; thus for those young women vaccinated between 2008 and 2014 they received a higher dosage of unknown impact. Young women are also socially, physically and emotionally encouraged to assume their gendered identities in engagement with feminine health practices. There is an unequal expectation on young women to protect the health of future generations, further burdening them with pressure, responsibility and engagement in patronizing and burdensome paternalistic medicine. The program sets up young women as being sexually responsible individuals who engage in health interventions in order to safeguard the potential "consequences" of sexual practices through, for example, responsible condom use and attendance of cervical screening.

In addition, it is the mothers of these young women who have taken on the additional caring role and have sacrificed their careers and businesses to stay at home and care for their daughters. Although it is speculative, I question whether the responses from clinicians would be different if this program had had such grave consequences on the lives and health of young men and their fathers. I also suggest that if young men were included in the UK's program, the ability for young women (and young men) to decline based upon previous side reactions, contraindications or underlying health issues would be absorbed and herd immunity (and fewer side effects) could still be achieved. This could reduce the gendered inequalities of the vaccine's prescribed social and health realities.

However, without other practice amendments being made, that is, parents receiving the PIL prior to consenting, school nursing teams respecting the wishes of parents to discontinue the vaccination and a greater willingness by medical professionals to recognize vaccine injury and side effects, the pharmaceutical burden of the HPV vaccine on young women will not be reduced.

The assumption that young women will participate willingly and compliantly in the HPV vaccination program is therefore a clear indication that the practices surrounding the pharmaceutical drug—that is, through the HPV vaccination program—do indeed "gender" the participants. Young women's bodies are not simply imagined as accepting and responding well to the pharmaceutical product; they are also expected to react in passive acceptance when side effects occur. A standard body responds in a particular way to receiving vaccines; it does not and should not experience adverse reactions. It is compliant and unproblematic. This is all part of what it means to be and behave as an appropriately feminine woman. Looking back at Milly, Gemma, Pollyanna, Marilyn and Stephanie's stories it is not difficult to see them as occupying a problematic position. These young women did not respond in the expected way to the HPV vaccinations. They are no longer young women on the anticipated trajectory into future healthy subjects. When there is deviation and deviance, as with the parents' challenges and claims of iatrogenic illness, the system and the state responds in ways which, according to the priorities of the young women's experiences, are unacceptable and/or extremely damaging.

I argue that young women are made responsible for ensuring the efficacy of the vaccine through the notion of being ideal healthy citizens, appropriately feminine in their health practices. Young women are expected to accept the vaccine, not to experience side effects, and are thus responsible for safeguarding their and their partners' future health. They are required to satisfy the standard prescription of the vaccine, acting out idealized conditions of being healthy, feminine and well women; that is why contraindications of previous illnesses are included in the PIL. It is therefore not difficult to see how knowledge of the HPV and vaccine is contestable, with varying accounts and stories from the experiences being presented in this chapter. Most notably the experiences of vaccine-injured young women and their parents are clearly in competition with those of the powerful medical and pharmaceutical industries. This has resulted in a precarious state of being for these young women, and as well as the life-limiting side effects. It also renders the project of appropriate femininity as impossible for them.

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9

Two Shots for Children

Lisa Lindén and Sina Busse

In February 2014 Austria became the first European country to offer the human papillomavirus (HPV) vaccine to both girls and boys for free. This chapter discusses how this has involved a discursive shift from the individual girl "at risk" to the population of children as the vaccination recipient. With the help of Adele Clarke's social worlds/arenas approach, we discuss the discursive positions taken by a range of different governmental and non-governmental actors concerning the HPV vaccine. Combining an analysis of public information material with an analysis of interviews with administration and health-care staff, the chapter highlights how gender, sexual disease transmission and immunization are articulated and discussed in the chosen social worlds of the Austrian HPV vaccination arena. In relation to that, we stress how a changed management of HPV vaccine evidence has crucial consequences for how the

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vaccination recipient and, in a broader sense, the Austrian population are constructed. We argue that the current discourse in Austria differs fundamentally from how the HPV vaccine often is framed as an individual, yet gendered, risk responsibility. In the current dominant Austrian discourse, herd immunity is anticipated through transformed relations between the individual and the population.

Three Shots at Prevention constitutes the title of one of the currently most prominent social science books on the HPV vaccine[1] (Wailoo et al. 2010). In Austria, the assumption that three shots are needed to prevent girls from being afflicted by cervical cancer in the future has changed into the assertion that two shots are sufficient. In addition, the focus on preventing *girls* from developing cervical cancer is changed into preventing *children* from developing a diverse set of HPV-related cancers. Looking at the HPV vaccine concept currently adopted in Austria, it becomes evident that it does not have to be "three shots for girls" but that it is equally possible to implement a vaccination scheme that is based on "two shots for children"—a change which opened up a broad range of possibilities for reframing the HPV vaccine's position in Austrian society.

In February 2014, Austria was the first European country to add the immunization of both girls and boys (aged nine)[2] with the HPV vaccine to its national school vaccination program (BMG 2014a). Austria is the second country introducing HPV vaccination for both boys and girls. In 2013, Australia was the first country to introduce a school vaccination program which includes the vaccination of girls and boys with the HPV vaccine (Australian Government 2013). By discussing how the

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[1] "[The] human papillomavirus (HPV) is a highly contagious infection transmitted through sexual or skin-to-skin contact" (WHO 2013). The virus is transmitted by men and women alike. There are over 100 different HPV strains (Gesundheitsinformation 2012). While most HPV infections disappear without treatment, a chronic infection with high-risk strains can develop into cervical cancer and genital cancer, including cancer of the anus, penis, vulva and vagina as well as mouth and throat cancers (Mishra and Graham 2012; Charles 2014). Gardasil, one of the two HPV vaccines on the market, has also been proven to prevent the infection with the HPV strains 6 and 11 that cause 90 percent of genital warts (WHO 2013). After the HPV vaccine's launch, it was mostly directed at the female population and constructed as "the girls' vaccine" (Mishra and Graham 2012).

[2] As is also the case elsewhere, in Austria the HPV vaccine is currently given for free only to boys and girls in fourth grade (nine years of age). The vaccine is not intended for everyone independent of age.

Austrian Ministry of Health, Austrian Cancer Aid (ACA), the Austrian Society of Gynaecologists and Obstetricians and the Working Group for Gynaecological Oncology as well as the Women's Health Centre in Graz in different ways negotiate and construct the HPV vaccine in Austria both before the decision to implement a gender-neutral vaccination scheme and now since the decision, we focus in this chapter on how the vaccine in Austria has been discursively transformed from a "girls' vaccine" into a "children's vaccine."

The change in government policy in Austria is interconnected with changed medical evidence articulations concerning the HPV vaccine. As has been discussed in science and technology studies (STS), the changed regulation of pharmaceuticals can carry with it societal changes regarding values and norms such as, just to mention a few, age and values of life (Will 2009), objectivity (Niezen et al. 2013) and, as especially relevant for our study, gender and sexuality (Fishman 2004; Johnson and Sjögren 2012). As we will discuss, the implementation decision of a non-gender-specific HPV vaccination scheme in Austria, in a similar way, is discursively interconnected with transformed articulations concerning the HPV vaccine's relationship to medical evidence and with changed constructions of gender and sexuality.

In countries other than Austria and Australia, the HPV vaccine has been directed at the female population and has been constructed as "the girls' vaccine" (Mishra and Graham 2012). STS scholars have shown that the HPV vaccine as a technology is entangled with gendered politics concerning girlhoods, sexuality and women's health responsibilities for disease prevention (Casper and Carpenter 2008; Epstein 2010; Mamo et al. 2010; Lindén 2016; see also Chaps. 6, 7 and 8 by Lindén, Maldonado and Hanbury, respectively, this volume). Thus, the HPV vaccine has been discussed as an example of a *gendering* of current public health with its focus on individual risk responsibility rather than population control (Mamo et al. 2010; Charles 2014; Burns and Davies 2015). For example, in the United States, the HPV vaccine has been first and foremost constructed through questions of personal lifestyle, individual risk and anxieties around young girls' sexuality. By the use of direct-to-consumer (DTC) advertisements a number of gendered health messages in this context have framed cervical cancer as a disease of innocence, detached from sexual connotations and directed toward the future health of individual girls (Mamo et al. 2010). Therefore, it has been firmly shown that girls in contexts other than Austria—such as the United States, the UK and Colombia—are constructed as the recipients of the vaccine and *not* boys, this through a focus on individual girls "at risk" for cervical cancer.

As a consequence of the general construction of the vaccine as preventing cervical cancer, male or gender-unspecific risks of HPV exposure, such as penile, oral and anal cancers, have been effectively sidelined in the majority of HPV vaccine contexts (Casper and Carpenter 2008; Mishra and Graham 2012; Charles 2014). In the United States it was first in October 2011, four years after the vaccine's initial approval, that the Centers for Disease Control and Prevention and the Advisory Committee on Immunization Practices recommended routine HPV immunization of 11- to 12-year-old boys (Mishra and Graham 2012). The silence on male risks in the vaccine's first years, the STS scholar Steven Epstein argues, was mainly due to sexual moralities that prevail in America and a prevalence of homophobia, since men who have sex with men have a higher risk of contracting anal cancer (Epstein 2010). When constructing the vaccine as a girls' vaccine, boys have often been made invisible as possible vaccine recipients, and other HPV-related cancers have not been seen as legitimate reasons for a non-gender-specific HPV vaccination scheme. Despite the fact that male subjects often are made invisible in the context of HPV vaccine, in Sweden males are made visible in this context as caring subjects who have a responsibility to encourage girls and young women to get vaccinated. In this way, they are not constructed as vaccination recipients, but as important actors in the arena of HPV vaccination (Lindén 2016).

However, boys can be relevant to an HPV vaccine discourse even when not positioned as recipients. For example, the STS scholar Andrea Stöckl (2010) argues that in Austria, questions of sexuality of teenage girls have not entered the debate on the HPV vaccine. Therefore, she argues, there has not been a discussion around female promiscuity, as was the case in the United States (Casper and Carpenter 2008). Additionally, she stresses, Austria seems not to have positioned the HPV immunization as a personal lifestyle choice, as was done in the United States (Stöckl 2010). Discussing the policy situation in Austria before the decision to include the HPV vaccine in the national vaccination program for both boys and girls, Stöckl (2010) suggests that in Austria the HPV immunization is generally understood as a public health initiative which has consequences for the whole population. Even though we largely agree upon this, and as we will discuss in this chapter, in Austria before the decision to implement the HPV vaccine in the national vaccination program, there was in fact (at least) one fear-evoking, individual-risk-focused and gendered campaign, partly similar to the ones in the United States. While certainly not representing the only framing of the vaccine before the decision to implement a gender-neutral vaccination scheme, drawing upon the social worlds/arenas framework (Clarke 2005), we still argue that this example is relevant when discussing situational and transforming constructions of the vaccine. However, the fear-evoking, individualized-risk-focused and gendered communication strategy has been transformed since the decision to implement a gender-neutral vaccination scheme, constructing the vaccine as a vaccine "for everyone" rather than for individual girls. In this way, in contemporary Austria, the vaccine is often presented as directed toward the health of the population and as important for herd immunity, similar to how vaccinations have typically been framed in history (Rose and Blume 2003). Consequently, now *after* the implementation of a national HPV vaccination program, we argue that Stöckl's (2010) argumentation holds but that it includes particularly intriguing expressions regarding questions of gender and sexuality due to the decision to include both boys and girls in it.

In Europe, where DTC advertisements are mostly prohibited (the exception is Sweden where DTC advertising is allowed for vaccines against infectious diseases in humans; see Lindén, Chap. 6, this volume), the vaccine has had to be introduced in a different manner than in the United States. In addition, Austria is different than, for example, the UK (Stöckl 2010) and Sweden (Lindén 2016) due to the fact that it was not until 2013 that Austria decided to finance a national vaccination program against HPV. Before the decision, the Austrian debate about the HPV vaccine was largely framed by a critique on the high costs of the vaccine and thus on the lack of a nationally funded immunization program (Stöckl 2010; ACA 2012). When the vaccine was first introduced in Austria in 2006, Austrian authorities had decided that it was not cost-efficient to state-finance the expensive vaccine. Since the vaccine was at this point still widely known as “the vaccine against cervical cancer” it was mainly girls and women who then decided to get vaccinated (Groth 2014). As a consequence they also had to accept the financial burden which came with this decision, namely, paying the costs of around €600 for three shots. Given the high price of the vaccine and a national vaccination rate that stagnated at 5 percent, many medical professionals and the Austrian Cancer Council (Österreichische Krebshilfe) started to criticize the Austrian approach and push for a free vaccination program (ACA 2012).

1 The Study

In our analysis we draw upon the situational analyses and social worlds/arenas framework developed by feminist STS scholar Adele Clarke (1991, 2003, 2005). This is an approach which acknowledges and considers the contextualization of the case study, something which is crucial for understanding the specificities of the constructions of the HPV vaccine in Austria. It is also a theory/methods package that enables discussions of negotiations between different actors (Clarke 2005). Therefore it provides a valuable theoretical tool for the analysis of the different discursive positions taken by different actors in the Austrian HPV vaccination context (Clarke 1991, 2005). According to Clarke, social worlds can be defined as “groups with shared commitments” (Clarke 2005: 46). Furthermore, social worlds share “resources […] to achieve their goals” and are built on “shared ideologies about how to go about their business” (ibid.).

The social worlds/arenas framework assumes that there are various social worlds which are part of a broader arena. Our analysis constitutes the “Austrian HPV vaccination arena” and helps us consider the multiplicity of positions taken in this arena. This approach makes it possible for us to analyze negotiations, convergences and conflicts between different ways of constructing the HPV vaccine in the Austrian HPV vaccination arena. Consequently, the different HPV vaccine social worlds are connected by their collective participation in the arena’s negotiations and conflicts. Hence, using Clarke’s approach, we discuss how Austrian institutions are involved in constant discursive negotiations concerning HPV vaccine.

We also use Clarke's (2005) approach to emphasize differences in actors' power positions. We stress the importance of not only powerful but also less powerful social worlds. This is why we include the Women's Health Centre in Graz as part of a social world inhabiting an alternative HPV vaccine discourse. In relation to the question of power, Clarke, moreover, underlines that silences in the data should not be erased but instead be addressed by the analyst (Clarke 2005). We therefore demonstrate where in the empirical material one can find silenced discursive positions.

The material from the chosen institutions or organizations has been selected on the basis of ease of access by potential recipients of the vaccine, or by parents who seek more information before they decide whether to get their child vaccinated or not. The chosen institutions or organizations (the Health Ministry, the Cancer Council, the network of Austrian Women's Health Centres, the Austrian Society of Gynaecologists and Obstetricians, and the Working Group for Gynaecological Oncology) have been chosen for their broad variety, including their distinct responsibilities and differences in size. From the institutions' or organizations' websites, nine different documents and publications were selected. The documents consist of public health campaigns and information material: patient pamphlets; patient brochures; fact sheets and an informed consent form. The average size of the different documents ranged from one to three pages. Here, the brochure published by Cancer Aid, however, stands out as the most extensive document with 23 pages (ACA 2012).

As an addition to the written material, this chapter includes empirical material from three interviews with three different health professionals: Dr. Patrick Müller from the Health Ministry, Elena Weber from Cancer Aid and Iris Schmidt who is a general practitioner in private practice.[3] The informants have been chosen on the basis of different organizational or institutional identification and, thus, different HPV vaccination social worlds.

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[3] To secure their anonymity our informants' names have been changed and their positions at ACA and the Health Ministry are not revealed.

2 A Girls' Vaccine or a Children's Vaccine Like Any Other?

Since the vaccine worldwide has initially been promoted as a girls' vaccine, it is important to analyze whether discourses are altered once the HPV vaccine is directed at both boys and girls. That such a transformation has actually taken place in the Austrian context is suggested by an awareness-raising campaign which was initiated in 2012 and which now, four years later, is no longer "in use"[4] (Groth 2014: 3). An example of this girl-centered campaign is a two-page leaflet, distributed by the Austrian Society of Gynaecologists and Obstetricians as well as by the Working Group for Gynaecological Oncology, which reads "Sometimes a vaccination can make the difference between life and death."[5] The leaflet was widely criticized by the network of Austrian Women's Health Centres for making use of biased statements and fear-evoking imagery. On the front page of the leaflet one can see a pink Venus symbol that is turned 180 degrees so that it now resembles a grave cross. In the top-left corner of the leaflet it is in addition written: "Cervical cancer can be lethal" (OEGGG and AGO 2014). In this pamphlet the HPV vaccine is constructed as a vaccine for girls and a vaccine against cervical cancer. During this time, it was criticized that the material was "printed with the kind support of GlaxoSmithKline and Sanofi Pasteur MSD": the two HPV vaccine manufacturers (of Gardasil and Cervarix) (OEGGG and AGO 2014). This statement prompted the Women's Health Centre in Graz to post a commentary in which the non-profit organization raised the question of whether the campaign had violated the Austrian law that prohibits DTC advertisements for prescription medicines.

Taking a look at the information material disseminated after the vaccine's inclusion into the school vaccination program in early 2014, it seems that Austrian officials decided to turn their awareness-raising strategy around. In an official announcement published on the Health Ministry's website in January 2014, the first sentence already reflects the gender-neutral discourse the ministry articulates: "Starting February

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[4] There are no links or references made to the campaign in the current empirical data.

[5] All translation from German to English is completed by Busse.

2014, the HPV vaccine is offered free of charge to all children living in Austria who attend Year 4 (nine years of age) under the existing school vaccination program" (BMG 2014b). In this sentence as well as in the rest of the announcement, it is striking that the ministry refers to "children" in general when mentioning the intended recipients of the vaccine. In addition weight is put on the fact that the vaccine will be part of the already-existing Austrian school vaccination program, established in 1998 and which offers free vaccinations to boys and girls alike. Thus, this program traditionally provides gender-neutral vaccination. Before 2014, the school vaccination program routinely offered 12 vaccines to schoolchildren, including the measles-mumps-rubella vaccine and the polio vaccine. In this sense the HPV vaccine is discursively put in line with other children's vaccines. Overall, this stands in contrast to how the vaccine has been constructed as a girls' vaccine in other times and locations. Instead of being a special vaccine for girls, it is positioned as just one of many other children's vaccines.

In the statement by the Health Ministry one can also read that the opinion "[t]hat the HPV vaccine would only constitute a shot for women, is long outdated" (BMG 2014a). This statement shows the ministry responding to the widespread assumption that the HPV vaccine constitutes a "girls' vaccine." The expression "outdated" stands out in this sentence, indicating that the ministry is using a progress narrative which rests upon an assumption of linear and continuous improvement in their vaccination program. By claiming as outdated the perception that the HPV vaccine is a girls' vaccine, they rely on recent scientific studies which have supported the vaccination of both boys and girls. Hence, implied in this announcement is the statement that new medical evidence has made the previous gendered assumption about the vaccine obsolete.

The assertion that the notion that the HPV vaccine would only constitute a technology for women is outdated is quite striking, given that the vaccine was already recommended for use for boys and girls when it was first launched in Austria in 2006. But at that time it was decided that the ministry could not afford a national HPV vaccination program at all (Stöckl 2010). This omission directs attention away from the fact that the change in the vaccination schedule was at least in part due to new price agreements between the Austrian government and the manufacturer Sanofi Pasteur MSD. It can be added that in the literature analyzed no explanations are given as to why the vaccine was actually once seen as the "girls' vaccine" in Austria (and still is in most parts of the world). Earlier awareness campaigns in Austria that clearly only directed their efforts toward the female population are not mentioned, either. This silence in the empirical material thus colludes in constructing the current child-centered HPV vaccination discourse in Austria.

During an interview for this study, Patrick Müller from the Health Ministry asserted that the decision to include boys in a national vaccination program against HPV was closely related to evidence showing that children under the age of 12 need to be injected with only two shots instead of three to be sufficiently protected. Müller furthermore argued that given the newly adopted "two-shot" vaccination scheme, the ministry would now be able to financially secure funding of the vaccine. He argued that it was when medical evidence made it clear that only two shots were needed it became economically possible to vaccinate both boys and girls.[6] As we will further discuss in Sect. 4, a combination of medical evidence and financial matters are here discursively articulated as reasons for changes to the vaccination scheme. The ministry's current discursive strategy can therefore be said to be connected to claims about, in Müller's words, "a broader vaccination spectrum, a new vaccination scheme and a clear decline in the price of the vaccine."

By articulating the recipients of the vaccine as "children," the Health Ministry made an effort to directly address "every child" right from the outset of their new vaccination program, which was introduced on the ministry's website (BMG 2014a). A gender-specific discourse regarding the vaccine recipient is generally absent from this new material. This is a surprising finding, when one considers that only two years prior an Austrian organization had launched an information campaign that solely addressed girls and women, using gendered components such as

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[6] This resonates with Stöckl's (2010) argument that the absence of a national HPV vaccination program in Austria has been connected to claims from Austrian health economists about the need to medicate both boys and girls to reach a state of herd immunity. According to her this led the Health Ministry to emphasize the Pap smear test as more cost-effective than the HPV vaccine.

a Venus sign and a bright pink layout. Even if this 2012 campaign had not been initiated by the Health Ministry, it still points toward the previous existence of a girl-centered HPV vaccine discourse in Austria that is absent from the current social world of the Health Ministry.

The public information material from the Health Ministry about the HPV vaccine generally lacks references and links to the previous vaccination concept. This can perhaps be explained by the criticism received by Austrian politicians regarding the lack of a national HPV vaccination program, prior to its inclusion in the school immunization program. A valuable example of this direct criticism can be found in a brochure written by ACA in 2012. In an introduction to the HPV vaccine, Professor Paul Sevelda, president of ACA, writes, "Austrian Cancer Aid has for years repeatedly appealed to Austrian political leaders to introduce a public and nationwide HPV vaccination program. The health of our children must be worth it!" (ACA 2012: 3). By using Sevelda's quote in its brochure, the charity articulates criticism against Austrian politicians and, by doing so, they position themselves as if they are speaking on behalf of the health of the population of Austrian children—unlike Austrian politicians.

Constituting a different social world than the Health Ministry in 2012, ACA—in contrast to the Health Ministry—pushed early on for a gender-neutral national HPV vaccination program. In their brochure from 2012 the charity's effort to position the immunization as a vaccine for both genders is evident. In the brochure ACA recommended HPV vaccination for boys and men by explicitly stressing that the vaccine may prevent not only cervical cancer but also a number of other cancers which are associated with HPV. Moreover, in the brochure it was stated that both men and women could contribute to the protection of the population by getting vaccinated (ACA 2012: 17). In this way, ACA constructed the vaccine as being about herd immunity, in contrast to its being an individual lifestyle choice. In sum, ACA had already by 2012 produced a discourse which positioned the HPV vaccine as an immunization "for everyone"—men and women alike. Thus, discursive positions articulated by the different social worlds of the Health Ministry and ACA in the HPV vaccination debate were in 2012 dissimilar. As we will discuss in Sect. 5, however, they are today fused together.

3 Individuals, Populations and Herd Immunity

Another important document that articulates the Health Ministry's current position is their Fact Sheet about HPV (BMG 2016). The information given in the Fact Sheet regarding the HPV risk for men and women clearly shows that the intended recipient of the vaccine is related to statements about the transmission of HPV. In the Fact Sheet, transmission of HPV is referred to as a chain of infection that "needs to be broken" in a joint effort by men and women. Breaking the chain refers to achieving a state of herd immunity. According to the document, the chain of infection will be broken much faster if both girls and boys are vaccinated. Once again, emphasis is put on how HPV is transmitted by both boys and girls, both men and women. Hence, both genders are articulated as transmitters, and this claim is used to argue that both should be vaccinated. In addition, by framing it as a chain that needs to be broken in a joint effort by both genders, responsibility for vaccination is put on both (they ought to *actively* break the chain by choosing to get vaccinated), in contrast to framing it as a responsibility of the state (or of girls; see Hanbury, Chap. 8, this volume).

In the Fact Sheet, the Health Ministry explicitly stresses that men "have a direct benefit" from the HPV vaccine, as HPV can cause genital warts as well as throat and anus cancers. This direct benefit is implicitly contrasted with the idea of men and boys as just helping girls and women to prevent cervical cancer. It is not only about girls' health; it also concerns the boys' own health. In this vein, the ministry highlights that on the one hand vaccinated boys help break the chain of infection faster, and on other hand, their immunization against HPV does not have to be seen as a purely altruistic step since Gardasil also protects against genital warts and various forms of cancers that affect men. The ministry hence underlines that there is "more in it" for men than commonly believed. Comparing this discursive articulation to the launch of the HPV vaccine in other countries, it becomes clear that the Health Ministry indirectly tried to debunk ideas about the HPV vaccine as a cervical cancer vaccine (cf. Wailoo et al. 2010; Maldonado (Chap. 7), Hanbury (Chap. 8) both this volume).

Claiming that the chain of infection needs to be broken in a joint effort by both men and women puts the focus on herd immunity. An emphasis on herd immunity is evident in the articulations made both by the Health Ministry and by ACA. For example, the ministry repeatedly uses terms such as "overall vaccination coverage rate," "herd immunity" and "herd protection" (ACA 2012: 4). In the Health Ministry's announcement, Austria's Minister of Health Alois Stöger is also quoted as saying, "[W]ith the inclusion of the HPV vaccine we make an important contribution to the health of the Austrian public. We will save lives" (BMG 2014a). The formulation that they will "save lives" puts the focus on herd immunity (see also Paul 2016). In a similar vein, ACA makes reference to herd immunity when stating that both men and women can contribute to the protection of the population by getting vaccinated. As it is a vaccine to achieve herd immunity, the population is often addressed in the information material.

However, by articulating that men "have a direct benefit" from the HPV vaccine, statements about individual health are also included in the Austrian discourse. It is not only for the "greater good" boys ought to get vaccinated; instead, it is something they can do for their own health. In this sense, it is not only the population that is addressed but also individuals. In contrast to how the individual has been constructed in other HPV vaccine contexts as a girl "at risk," in the dominant discourse in Austria today the HPV vaccine recipient is not defined by his or her gender. For example Dr. Iris Schmidt, a general practitioner and doctor in private practice, argued in her interview that she believes that most parents will consent to the HPV immunization of their children now that it is offered for free. In the case of state-financed HPV vaccine, the parents' decision to vaccinate is therefore, in her eyes, also no longer influenced by their child's gender. Moreover, Schmidt suggested that this would be even more the case when education of the Austrian public is guided by a discourse that puts an equal effort into emphasizing the risk of men developing malignant tumors from a chronic HPV infection.

Individuals are also addressed when the topic of personal decision making is brought up. Elena Weber from ACA, for example, emphasized in her interview that it is in no way the organization's aim to "proselytize" the Austrian public. Rather, it is the charity's goal to present material that can function as the basis of decision making for parents. Here, the position of ACA is articulated to be about guiding individual parents regarding vaccination decisions. In a similar way, in their information material, ACA underlines that it is completely up to "you" to decide whether the immunization constitutes the right step (ACA 2012: 10). Taken together it can therefore be inferred that the Health Ministry and ACA put forward a discourse which conveys the idea that the public is provided with a "factual" basis for individual decision-making practices. As a consequence, the Austrian citizen is put in a position in which he or she has to decide for him- or herself whether to get vaccinated. At the same time, however, the information material also contains references to the overall and population-wide benefits of the HPV vaccine. In short, the message communicated by Austrian institutions thus implies: *Decide for yourself, but keep in mind that HPV can affect everyone!* On the one hand this twofold message quite obviously informs the public that both men and women should consider the vaccination. On the other hand, however, it also reminds the public that since everyone can in principle be affected by the viruses, the population has the chance to work together in an effort to eliminate different forms of HPV infection, a discourse that articulates that there is an important connection between the individual level and the population level. Individual action is presented as closely connected to population goals.

Additionally, the Austrian Ministry of Health and ACA seem to indicate that the decision to get vaccinated should not take place in isolation, meaning that one is wise not to consider only one's own health and personal benefit. In this context it is, for instance, stressed in the ACA brochure that boys and men should take into account that passive carriers of HPV can become active vectors of disease (ACA 2012: 12). As a consequence the vaccine is positioned as a vaccine to protect "everybody"—girls and boys, men and women—and to help everyone, too. With this current focus on the vaccine as a vaccine for everyone, with the dual focus on individual benefits and population goals and with the emphasis on herd immunity, the previously very different social worlds of the Health Ministry and ACA are today fused into one.

4 Medical Evidence, Costs and Benefits

Patrick Müller from the Health Ministry pointed out that the recommendation to vaccinate boys and girls had "always existed" but that funding for the current broader vaccination spectrum had not been secured until 2014. Elena Weber from ACA also claimed that it was mainly for "financial reasons" that it took the Health Ministry years to include the HPV vaccine into the free school vaccination program. Müller, again, quickly emphasized in his interview that the Health Ministry usually clearly places financial issues related to the funding of an immunization program at the center of attention. On being asked whether it was because of the initially high costs of the vaccine that first only girls were targeted in awareness campaigns, he responded that the state was simply not able to finance the vaccine for either girls or boys prior to 2014. The state, Müller asserted, was thus only able to finance the vaccine for preteens (9–12 years) once the government and the stakeholders involved had agreed on a much lower price for immunization during a recent tendering procedure. Müller emphasized in 2006 that the Health Ministry was already convinced that both girls and boys would benefit from Gardasil. In his opinion, the high and private costs of about €200 per dose (€600 in total) therefore fostered the public's reservations about the HPV vaccine. Given these circumstances, it is not surprising that until 2014 more women than men were willing to "pay the price" for the vaccination. And even though more women than men had been vaccinated, the vaccination coverage rate prior to 2014 amounted to only 5 percent—a number that is described as a "sad world record" in the ACA brochure (ACA 2012: 4).

By claiming that the vaccination of both boys and girls would lead to a general reduction in HPV infections in the whole population, the Health Ministry articulated herd immunity as a goal firmly established in its new vaccination concept (BMG 2013: 2). In the interview with Müller, it became clear that cost-effectiveness analyses often took on a central role when a country established its vaccination schedule. Doing so, it is "very important to carefully select the right kind of benefit," Müller underlined. He asserted that in Canada, officials also argued for herd immunity but at the same time they had put forward a cost-effectiveness analysis for cervical cancer as their evidence. When they then calculated whether the immunization of boys could also be cost-efficient, they had to assume there would be a duplication of costs. Müller therefore highlighted that doubled costs would not have resulted in economic benefit, since Canada had considered only cervical cancer as its benefit. In the Austrian calculations, however, the fact that Gardasil is a quadrivalent vaccine which also protects against other forms of cancer and genital warts was considered. Müller asserted that if one also considers the costs that arise from the treatment of other carcinoma and genital warts, the vaccination of both genders turns out to be more favorable. In addition, the use of evidence that two shots (instead of three) are enough for children up to 12 years old illuminates how a different use of evidence enables a shift from a girl-centered HPV vaccine discourse to a "for everyone" discourse. This was commented upon by Müller, who said that "what really is evidence here, well there is a broad 'spectrum.'" He asserted that if one would, for instance, also take into account that "we will only see the first prevented case of cervical cancer in 20 to 30 years' time, such calculations can't be cost-effective." Looking at Müller's statement, it therefore can be inferred that in Austria the protection of the whole population has been constructed as the goal. In using a "broader range" of evidence and by aiming at the eradication of genital warts, the Health Ministry seems to have moved away from a tight vaccination budget. Moreover, using health-economic arguments as justification for the importance of including both boys and girls in a national vaccination program, the current Austrian discourse is legitimized. As STS scholars have argued (Ashmore et al. 1989; Sjögren and Helgesson 2007), cost-effectiveness as a health-economic calculation tool is not a neutral phenomenon but something entwined with values and norms. Emphasis on the cost-effectiveness of the HPV vaccine in Austria is connected to articulations of medical evidence, including certain choices regarding what to include in health-economic calculations and what to leave out. Importantly, this illustrates how health-economic calculations as medical evidence are contingent social activities that are formed in interpretative practices.

Finally, because of the Health Ministry's selected evidence, which supported its goal of achieving herd immunity, the ministry was able to construct the vaccine as a public good that has the population—not just girls—as its target. In this sense, how evidence is managed and negotiated along with financial matters made it possible to transform the vaccine from a "girls' vaccine" directed toward girls' individual health to a vaccine "for everyone" aiming at herd immunity.

5 Discussion

Using social worlds/arenas and situational analysis as our theoretical approach, we discussed the discursive transformation in Austria of the HPV vaccine from a "girls' vaccine" into a "children's vaccine." In accordance with the decision to implement a national HPV vaccination program for both boys and girls, the one-sided and gendered depiction of immunization as a girls' vaccine against cervical cancer moved to the background in favor of a discourse about a children's vaccine against a diverse set of cancer forms and genital warts. We discussed this as an emergence of a transformed dominant discourse—a discourse which is no longer built upon the assumption of "three privately financed shots for girls" but instead on the construction of "two free shots for children."

We argued that the current children-centered discourse is partly connected to articulations made by ACA back in 2012. Partly therefore, and in connection with the Health Ministry's decision to modify its vaccination concept, we asserted that the initial two separate social worlds of ACA and the Health Ministry have merged into one world. This is partly done by making absent the girl-centered HPV vaccine history from current articulations.

First and foremost the discursive position pushed by the Health Ministry and ACA is based on the goal of herd immunity. The only instances in which explicit references to the individual were made in the materials studied were in relation to the discussion of the individual's (or parents') freedom to choose for or against the vaccine, and in connection with articulations of boys as directly benefiting from the vaccine. In addition, it is striking that little to no attention is directed in the contemporary discourse at the discussion of the individual's future health and present risks. This constitutes the Austrian case as not only different due to its inclusion of boys in a national vaccination program but also by emphasizing herd immunity instead of individual risk (cf. Wailoo et al. 2010; Paul 2016).

In the current Austrian discourse the articulation of HPV infections as a chain of infection that "needs to be broken" stands out as an important construction of relations between the individual, the population and the possibility of herd immunity. The metaphor of the chain connects individual actions with population goals. Citizens are addressed as individuals that together can act to achieve herd immunity. The chain metaphor allows for a combination of an individual-focused and a population-focused public health intervention discourse.

In critical public health studies it is often discussed how a current public health focus on individual risk and personal choice is gendered (Daykin and Naidoo 1995; Moore 2010). As we indicated in the introduction to this chapter, the HPV vaccine is, therefore, often discussed as an emblematic case for a critical discussion around a gendering of current public health. In this chapter we have shown that other dominant discourses can emerge in connection with changes in governmental regulation. Consequently, in the current dominant Austrian discourse, the individual is focused on in a way that is partly different from what Aronowitz (2010) refers to as an HPV vaccine "individual-by-individual population-level intervention" (Aronowitz 2010: 34). In contrast to other HPV vaccine contexts, an individual, yet girl-centered, risk responsibility is not part of the current dominant Austrian HPV vaccine discourse. This discourse does not position girls' bodies as more "risky" than boys (cf. Aronowitz 2010; Wailoo et al. 2010; Mishra and Graham 2012; Lindén 2016). In contrast, the dominant Austrian discourse today highlights transformed relations between the individual and the population, and articulates a gender-specific construction of the HPV vaccine as obsolete and outdated. This study articulates questions of not only who is the intended vaccine recipient, but also what constructions of sexual health are made, whom to protect, and why, the valuing of medical evidence in current society and the distribution of responsibilities between citizens and health authorities.

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10

Sexing Drugs, Refracting Discourses

Ericka Johnson

This book has discussed the way pharmaceuticals can produce sex/gender[1] and be sexed/gendered in many different contexts. It presents empirical cases, covering pharmaceuticals on both ends of the adult subject and sex/gender in many different contexts. As such, it is an attempt to show the productive benefits of applying feminist technoscience studies' theoretical tools about material-discursive entanglements and subjectivity to pharmaceutical studies and the political traction this can produce.

I suggest that the discourses discussed in previous chapters have been refracted—articulated, clarified, separated—into a colorful spectrum of concerns, ideologies, assumptions, presumptions, values and norms as they have been read through the pharmaceuticals. When clarified through the refractive prism of a drug, this metaphor allows us to ask: Which assumptions become visible? Which aspects of the subject have

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[1] See Chap. 1 for a discussion of terminology around sex, gender, trans and so on.

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attracted pharmaceutical attention? What does that attention do to our bodies? What subject positions do pharmaceuticals enable?

The collection of chapters here shows how different discourses are encountered in different contexts, and how pharmaceuticals can articulate these differences, even while traveling across nation-state borders and between cultural contexts as allegedly context-independent, ontologically discrete products. Much of the medical policy in Western/Northern countries tends to assume that there is a single body which responds in a predictable way to particular chemical compounds (cf. Epstein 2007). Yet pharmaceuticals are flexible, mutable and context dependent, as science and technology studies have long asserted all technologies are. Or, as claimed by the particular theoretical approach used by many of this book's authors, technologies are material-discursive entanglements which are performed in very context-specific ways to produce particular knowledge phenomena.

The reader may wonder why the contributors have chosen to focus on the discourses of sex/gender when studying various pharmaceuticals and their understandings of the "healthy" adult subject. The answer is because much of the feminist *oeuvre* has been an attempt to challenge existing power structures, discursive ones as well, even when they are initially invisible. If they are to be challenged, they must be articulated, so we know what is being said to and about us as embodied subjects and so we know where, what and to whom to protest, deny, disagree with or possibly even to embrace. This is a feminist political position. This book is an attempt to initiate a political stance about pharmaceuticals and sex/gender discourses of the body.

Against this background, the chapters here show that medicine can, among other things, create sex/gender. As detailed in the introduction (Chap. 1), the authors have also been open to using "sexing" or "gendering" in verb form and the assertion that pharmaceuticals can "do" this, which is one of this book's key contributions. Within feminist technoscience studies, it is not unusual to think about practice and performativity in discourses. However, this book wants to point out that pharmaceuticals themselves can be active agents in the enactment or performance of sex/gender and in the way sex and gender and drugs are implicated and act in social and power relations. In the discourses examined, not only are pharmaceuticals positioned as (sometimes necessary) components for the realization of healthy subjectivities with strongly gendered components, but they have also been found positioned between people as a necessary component of gendered relationships.[2] This is seen occurring with prostate treatments, Alzheimer's medications and even a seemingly innocuous vaccination against cancer. These drugs have been posed as necessary to produce appropriate, and gendered, partnered and intergenerational relationships.

The different studies presented in this book also highlight that sex/gender is only one of many different categories that are produced from or—perhaps more correctly—that produce social difference. Class, access to capital, race, ethnicity, age and geographical location appear in the chapters, and there are many more, which could—and should—be included in the analysis. Because of this, many of the authors have tried to approach their fields through a theoretical lens inspired by the concept of intersectionality and its development from *within* (Crenshaw 1989; Lykke 2010) and *beyond* (Moser 2006; Yuval-Davis 2006) the heterogeneous field of women's/feminist/gender studies. This work inspires the analysis here, even as chapters in this book focus on sex/gender in pharmaceutical discourses.

1 Refraction and Material-Discursive Pharmaceuticals

The reason this book has looked at discourses *and* pharmaceuticals to examine "healthy" subjectivities is because, for most of the authors in this book, pharmaceuticals have been conceived of as material-discursive entanglements. Following Barad, and within agential realism, the material and the discursive are entangled. They are not ontologically discrete, cannot be conceived as separate or existing apart from each other, and thus the hyphen in material-discursive (Barad 2007: 810).

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[2] This has been explored elsewhere at length with the obvious example of Viagra, a drug that is often discursively positioned as a necessary component for sexual and sometimes emotional relations between people; see Mamo and Fishman (2001); Marshall (2006); Tiefer (2006); Johnson et al. (2016).

This entanglement is the way the world is "mattered," or made to be. Discursive cuts are then made around objects, creating boundaries, creating identified "things." But these "things" are practices, phenomena and, to some degree, arbitrary, and very political, and local. Thinking about pharmaceuticals through this approach imagines drugs that are material-discursive entanglements, which become mattered through boundary-making practices, cuts which come down in particular ways in particular places for particular people. The material of the drug is not prior to the discourse, but neither is the discourse prior to the drug (cf. Barad 2003: 822). Yet, I suggest, once the cuts have been made, a particular pharmaceutical matter within the phenomenon of knowing it can also help us refract[3] the discourses it is entangled within. The pharmaceuticals refract a spectrum of unique, context-specific discourses, making visible values, understandings and ideologies; making visible a spectrum of concerns we are living with. Seeing these allows us to respond to these discourses so we can (must) pay attention to the values at play in the material-discursive entanglements which the pharmaceuticals are, and which they articulate. The specific cuts that make a pharmaceutical, the particular material-discursive entanglement known as a pharmaceutical, allow us to see the spectrum of concerns produced for us to resist or embrace.

While I am using the concept of a spectrum to illustrate the idea of contours and colors of the discourses articulated by the pharmaceutical, I would like to remind the reader that the concept of spectrum is much more than just a physical refraction of light into a standard rainbow

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[3] Please note that I am using the term "refraction," not "diffraction," even though I am proposing "refraction" within the same theoretical framing of material-discursive approaches to materiality that has generated the concept of diffractive reading. Refraction is different than diffractive reading, which was suggested by Haraway (1997) and developed by Barad (2003) as a way to step away from reflection. I understand diffractive reading as a method to combine ideas from diverse theories, theorists and fields, to find ways to see new things. As Barad poetically puts it, "Like the diffraction patterns illuminating the indefinite nature of boundaries—displaying shadows in 'light' regions and bright spots in 'dark' regions" (Barad 2003: 803). The usefulness of this approach when theorizing about technology is demonstrated by work from Hoel and van der Tuin, who use diffractive reading as a "new methodology for working with philosophical texts" that allows them to bring together previously disparate theories as resources for contemporary work on technology (Hoel and van der Tuin 2013: 190). The approach is equally useful for questions of gender and sex, as when Jagger applies it in her analysis of new materialism and sexual difference (Jagger 2015), and as a way of rethinking ethnography (Schneider 2002). But it is different than the refractive untangling of material-discursive entanglements I'm proposing here.

pattern. A spectrum, as Mehrabi applies it in her study of the spectrum of killability in a lab (Mehrabi 2016), is also a concept that has been used repeatedly in discussions about sex and gender, and sexuality. Relying on Barad's agential realism, Mehrabi (2016) discusses the spectrum as a performed series of cuts and hierarchies, which, in the context of this book, reminds us that discourses are being performed, together with the pharmaceutical. But when seen through the pharmaceutical, their contours become more easily articulated.

Within this framework, ontology is relational, again highlighting the importance of context, of time and place. This is why the empirical exercise of examining, making visible, articulating the discourses entangled in the pharmaceutical (over and over again, every place it appears, in different times and locations, because the concerns are unique to each entanglement) is important. So, to return to the examples in previous chapters, by refracting discourses through pharmaceuticals, the various pharmaceuticals in this book have articulated discursive contours shaping subject positions and relations, for humans of different citizenships, abilities, class, ages and sex/genders (and for animals).

In Mehrabi's work, one can read her observations as a refraction of how in the sexing of flies, the (not yet even developed, but imagined) pharmaceutical is embedded in a scientific discourse which relies on an understanding of binary sex, bodies as belonging to one of two categories, and the association of binary sex with biology. But, as Jagger so clearly articulates in her critique of sexual difference (Jagger 2015), and as Kraus also examines in her work with flies in the laboratory (Kraus 2000), this is a discursive construction. Viewed through pharmaceutical knowledge production practices, the binary sex of Mehrabi's lab, as well as its belief in a genetic component to Alzheimer's disease research, becomes clear, and also opens up the question of what these do for the knowledge produced.

Roberts and Cronshaw (Chap. 4), on the other hand, used their analysis of the hormone treatments for trans adolescents to show how pharmaceuticals, when positioned within specific trans discourses, can refract understandings of trans identity which are richer than the binary sex model that Mehrabi encountered. They articulate a new identity, that of the trans child. Their analysis of the discussion and use of these hormones is political in and of itself, but it is also interesting embedded in this book, as it shows how discourses around us are varied and heterogeneous, and pharmaceuticals can create identities in varied and heterogeneous ways.

In Chap. 3, in which I examined the use of alpha-blockers to treat enlarged prostates, I used a close reading of the medical guidelines to see how alpha-blockers were addressing the concerns about urination frequency which were impacting the patient's ability to perform normal, "healthy," urination practices. These evaluations, which were drawn from studies imprinted by class- and culture-specific activities, such as long car trips, golf games, and theater performances and movies, are discursively associated with male bodies, and the prostate as the anatomical source of a male problem.

Part II looked at commercial images used to promote pharmaceuticals. Here the discussion focused around the relationships that were promoted for the imagined subjects in the advertisements. By refracting the discursive contours of the relationships imagined to be facilitated by these drugs, these chapters showed some of the characteristics that are attributed to those relationships, and therewith also expected of the subjectivities participating in them. The pharmaceuticals articulated discourses about the value of care across relationships, within the heterosexual dyad and also across generations, as well as the idea of freedom, pleasure and the normally functioning body as a precursor to homosocial and heterosexual relationships (in contrast to the men-only discourses around the prostate in the medical guidelines). They also showed the value placed on the mother–daughter relationship that is being enabled by the human papillomavirus (HPV) vaccine, and the way it is related to a Swedish ideal of mother Svea, nature, freedom. In all of these, the interpersonal and intergenerational relationships, the subject is not alone, and even as an aging subject and as a youth, the person targeted by the pharmaceutical is imagined as in relationships with other "healthy" adults. The subject is not isolated, but is social.

When thinking of the pharmaceuticals as refracting and articulating the contours of discourse—clarifying or making visible values, ideas, subtle and even unspoken understandings, studies of the same technology in different contexts become particularly relevant. This becomes apparent when the authors in the final chapters examined the material-discursive subjects that are entangled with HPV vaccinations in the UK, Colombia and Austria. The different discourses refracted through the vaccine tell us both something about the embodied subjectivities in the respective contexts and also something about the technologies. Part III, the final part, shows how, when the same drug (HPV vaccine) is entangled in different discursive contexts, it refracts a very different spectrum of concerns and takes on very different discursive contours.

Thus, in the Colombian context, race, class and gender were reshaped in the local context through the association of cervical cancer with sexual promiscuity (by women and through their interactions with promiscuous men). This rendered invisible other cancers associated with HPV and resulted in vaccination policies that targeted impoverished girls and, initially, the daughters of prostitutes. HPV vaccination was produced to be both a display of state benevolence and a tool to promote social equity and female empowerment.

In the work about vaccine-injured girls in the UK, pharmaceuticals refracted ways injured bodies and dissenters challenge discourses of girls' embodied responsibility for the health of the herd. Exploring responses to injured bodies from medical experts, and school vaccination information to promote healthy bodies, Chap. 8 finds the HPV vaccine refracting discourses of female responsibility for the population's health in general and the (assumed male) future sexual partner's health in particular.

Finally (Chap. 9), by entangling pharmaceuticals in a context which has chosen to vaccinate all bodies of a certain age, regardless of physical or experienced sex/gender, the case of HPV vaccination in Austria refracts a concern for the herd and population health. The use of the metaphor of a chain of infection displays a shift away from the discourses of individual (future) risk, and away from the association of HPV with only cervical cancer.

2 "Healthy" Subjectivities

Applying refraction as a theoretical tool to the empirical analysis of pharmaceuticals and healthy subjectivities has allowed the work in this book to articulate unspoken norms, values and understandings in the discourses, which are part of the material-discursive entanglements that are pharmaceuticals. It has articulated the discursive associations of pharmaceuticals with “healthy” subjectivities, and some of the characteristics of these imagined subjects.

The communicative landscapes of drug advertisements, medical guidelines and papers, internet forums, printed literature, vaccination campaigns and resister discourses display thus not only a particular health culture, but also ways of identifying or disidentifying with cultural health regimes. They position and prescribe a particular modus of becoming what is regarded as a “healthy” subjectivity. The approach many of the authors in this book take to subjectivity does not distinguish between personhood and its discourses. A common way of understanding the relationship between personhood and discourses is that discourses surround us in a media- and image-saturated world, but that they are very distinct phenomena. This common distinction between subjects and discourse has inaugurated public debate on how media images and popular culture affect people—often in terms of describing the receiving audience either as a blank slate awaiting cultural inscription or as composed of rational individuals, selecting for identification the most advantageous ideals and images suiting his or her goals in life. However, within a poststructuralist approach, cultural and social theory has developed an understanding for how identification, or disidentification for that matter, works in subtle yet ubiquitous ways in our everyday life practices. Such theories suggest that there is no way anyone, or anything, today can stand outside of culture, its images, ideals, suggested values and ways of knowing or talking about ourselves, others and the surrounding world. Human personhood is shaped in constant interaction with surrounding communications, in the meeting with surrounding messages and suggestions, modes of talking about things and images that spur previous conceptions. And, as many in feminist technoscience studies argue, so are technologies such as pharmaceuticals. This is perhaps most obvious in the cultural genres of advertising. Here the targeted subject feels hailed into existence, addressed and touched by how well the message engages or confirms his or her feelings of vulnerability and lack, or his or her dreams or ideals for future existence full of successful relationships and social accomplishment. But, as the work here shows, it is also relevant in scientific, medical and policy discourses, as well.

Subject positioning is an analytical concept used in social theory to discuss the way images, movies, stories, texts of different kinds and the material world appoint an ideal or desired position of identification for its intended readers or viewers. There is an ideal consumer that, for instance, HPV campaigns seek to address, and that ideal position or subject position can be traced and analyzed in the campaign material, be it videos, advertisements, slogans or information sheets. This means that, implicitly or explicitly, the imagined and targeted receiver of the communication is addressed by way of gendered, age-related, sexualized and radicalized, nationalized cultural codes and social systems of knowing and relating to these intersecting societal categories. In the humanities and social sciences, this has instigated a general move in qualitative research from studying images or texts in themselves, to studying the mutual co-constitution of text and reader, image and viewer. Cultural regimes, prescriptions for shared ideals, norms and ways of inhabiting our cultural citizenship can thus be read out of such analyses, as has been done in this book.

Thus, the authors here have examined scientific, medical, commercial and user/dissenter texts, images and practices to articulate the multiple discourses that attach pharmaceutical treatments to the healthy subject with a sensitivity to concerns often found in feminist science studies, in particular awareness of intersectional issues related to class, gender, sexuality, ethnicity, age and location (Martin 1992; Oudshoorn 1994; Fausto Sterling 2000; Thompson 2005; Suchman 2007; Mol 2008; Lykke 2010; Murphy 2012;). They also draw on and hope to contribute to studies of science, technology, and society and medicine, examining what medicine does to and by us, today, like the work of Mol (2002), Law and Singleton (2005), Johnson and Berner (2010), Löwy (2015) and Roberts (2015). And in the process, they have articulated a spectrum of discourses the drugs refract.

Refraction can make visible discourses in which the drugs are embedded and the work they do for those discursive concerns, and perhaps change the way we think about pharmaceuticals. Specifically, by refracting discourses through the lens of a pharmaceutical, one can think about what material-discursive subject contours are being addressed by the drugs, and ask why those specific contours of the self are important enough to warrant medical attention. Why do those discursive contours attract the costly, painful and sometimes debilitating attention of the medical establishment, and why are they important enough for a patient (and his or her collective of relatives and friends and other social contacts) to think it is necessary to change that contour? Here the academic aspects of our studies suddenly become political. Our work can demonstrate the cultural values that are confirmed and affirmed, done and redone, reproduced, strengthened, heightened, resisted or embraced with the construction of bodies and subjects in and by pharmaceuticals at several different parts of the pharmaceutical nexus. And it shows that there is not a singular pharmaceutical product which works on a standard body, because the medical subject, the embodied patient, is a context-specific material-discursive entanglement, just as the drugs used on it are, as well.

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