# Medical Knowledge and Uncertainty: Health Professionals' Narratives of Childhood Vaccines

by

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A thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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#### Abstract

In recent years, narratives about various embellished and imaginary risks of vaccination have come under criticism because of their implications for the widespread acceptance of vaccines. Criticisms of these narratives often accompany assumptions that all mainstream health professionals accept, value, and promote vaccination. Most health professionals, however, are socially situated between vaccine experts (such as immunologists) and the wider public. In fact, since the first smallpox vaccine, professionals and the public have expressed somewhat varied understandings of the costs and benefits associated with vaccines. Health professionals' views are more uniform than they were in the late 1800s, but most of the literature about vaccine anxieties focuses on public and patient perspectives. While some studies have analyzed health professionals' understandings of vaccination, the focus on lay perspectives helps maintain assumptions that all health professionals are aware of the current state of vaccine knowledge and fully accept the necessity of vaccination.

This dissertation challenges assumptions about health professionals' relationship to vaccination through the analysis of thirty-four semi-structured interviews with twenty-seven physicians and seven nurses who were practicing in central or southern Alberta. During these interviews, health professionals described their experiences, knowledge, and uncertainties regarding vaccines. Interviews centered around four separate but related topics, which comprise the bulk of this dissertation. First, professionals accounted for what they perceived to be the risks and uncertainties associated with vaccination, pharmaceutical products, and vaccine policies. Second, interviewees appeared to use tactics to maintain their support of vaccination despite their perception of the risks or uncertainties associated with specific vaccines. Third, while managing their uncertainties, interviewees provided individual accounts of themselves that emphasized

their own professionalism. These accounts often involved a comparison to other professionals and patients, who they presented as misinformed. Fourth, interviewees problematized the role of media, social networks, and celebrity endorsement in public conceptions and fears of vaccines.

Throughout interviews, health professionals used personal stories about vaccine risks and benefits to express their role, the risks of disease, and potential risks associated with vaccination. Indeed, many people, including health professionals, share and learn about vaccines through various forms of narrative, which convey both information and emotion. As such, this dissertation offers some insight into the role of narrative in the communication of medical knowledge, the potential diversity in health professionals' understandings of a mundane public health treatment, and the ways in which individuals create professional presentations of self when they are situated between experts and the public.

# Preface

The research project, which includes dissertation, is the original work of Terra Manca. The Research Ethics Board and Health Ethics Board at the University of Alberta approved this project "Vaccination, Medical Knowledge, Practice, and Uncertainty," No. MS4\_Pro00040165, on July 21<sup>st</sup>, 2014 with Dr. Stephen Kent listed as the primary investigator.

While completing this dissertation, Terra Manca published an article titled, "Health professionals and the vaccine narrative: 'The power of the personal story' and the management of medical uncertainty," *Journal of Health, Risk, and Society*, vol. 18, issue 3-4, 114-136.

#### Acknowledgements

There are many people who helped me complete this project in a variety of ways. First, I extend thanks to Dr. Stephen A. Kent who has generously offered his support and time since he met me in 2005. I do not have enough space to fully express the impact of his confidence in my abilities, feedback on my work, and efforts to push me beyond what I perceived to be possible. In addition, I thank Dr. Amy Kaler for her perspectives regarding the design of this project, editorial comments, and substantive feedback. I am also grateful for the early guidance from my candidacy committee members Dr. Tim Caulfield and Dr. Laurel Strain. Moreover, my doctoral committee members Dr. Robyn Lee, Dr. Sharon Preeves, and Dr. Ubaka Ogbogu offered constructive comments regarding the final stages and future directions of this work. Furthermore, I extend gratitude to Dr. Robin Willey for discussing this topic with me, proofreading various manuscripts, and offering editorial commentary. Finally, I am grateful for the feedback I have received from conference delegates, journal editors and reviewers, and informal conversations during the writing phase of this project.

My friends and family have been incredible through all my efforts, successes, and frustrations while working on this project. I thank you all, and especially Craig Manca, Dr. Donna Manca, Stephany Manca, and Anne Manca. My partner, Dr. Patrick McLane offered invaluable comments to help me grapple with various issues that came up throughout this project. Dr. McLane also offered remarkable support, insight, and at times, much needed distraction. Lastly, much of this dissertation was written under strict supervision of my cats (Turbo and Nitzel), and with mandated walk-breaks with my dog (Lucy).

Throughout the duration of this project, I received substantial funding from various sources. These included Izaak Walton Killam Memorial Trust (Izaak Walton Killam Memorial Scholarship), the Social Sciences and Humanities Research Council of Canada (Joseph-Armand Bombardier Canada Graduate Scholarships), the University of Alberta (President's Doctoral Prize of Distinction and the Dissertation Fellowship), and the Department of Sociology research grant.

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## **Chapter One**

#### Introduction

In the summer of 2016, two Albertan parents were sentenced for failing to provide the necessities of life to their unvaccinated nineteen-month-old son, Ezekiel Stephan. Ezekiel died from a lung infection and meningitis, against which the province vaccinates free of charge, and from which children often recover with timely medical care (CBC, 2016; DiManno, 2016). His parents were charged because while their son struggled to breathe, they responded to his condition with prayer and non-medical remedies—such as hot pepper, garlic, onions, horseradish, and Echinacea tincture (CBC, 2016; Common, 2016; Graveland, 2016). Ezekiel's father, David Stephan was sentenced to four months in prison, and his mother, Collet Stephan was sentenced to three months of house arrest (Graveland, 2016). Throughout their trial, David Stephan built a narrative that positioned himself as a victim of pharmaceutical and vaccination interests. David Stephan alleged that the attacks upon his wife and himself reflected the agenda of those who were to criminalize parents who forgo vaccination:

'parents who choose not to vaccinate have a greater onus to seek mainstream medical attention sooner than parents that do not vaccinate, and if any harm befalls the non-vaccinated child from an illness that there was a vaccine for, the parents can be held criminally liable' (David Stephan in DiManno, 2016).

In an interview with the media, legal scholar Tim Caulfield voiced concerns that Stephans' narrative could reappear throughout anti-vaccination discourses that would construct the couple as martyrs (Graveland, 2016). In particular, film producers interviewed the Stephans in relation to their vaccine critical documentary called *Vaxxed: From Cover-Up to Catastrophe* (Graveland, 2016). Alternatively, Ezekiel's case also offered a powerful narrative for medical supporters because it was a personal and tragic account of the risks of forgoing vaccination and medical

care. Cases, as severe this one, demonstrate the severity of the possible effects of the vaccine ambivalence and narratives that I investigated for my doctoral research.

Furthermore, Alberta newspapers reported about the spread of various vaccine-preventable diseases and about vaccine uptake rates during the years I spent in the PhD program at the University of Alberta. Although some newspapers and other media outlets sensationalized perceived risks and fears of vaccination, the culturally dominant vaccine narrative asserted that vaccines are the safest and best means to prevent disease (Heller, 2008). That is, the vaccine narrative, as a grand story about the success of medicine, offered a palpable, emotional, and simple explanation about how to avoid death and morbidity.

The dominance of this narrative is notable in government vaccination guidelines. For instance, the Canadian government vaccine guidelines supported the culturally dominant vaccine narrative, by asserting that vaccines are safe, effective, and necessary. For example, the Alberta Immunization Strategy (2007-2017) stated:

Immunization has often been cited as one of the greatest medical success stories in human history. [...] In fact, research shows that with the exception of clean drinking water, no other human intervention surpasses the impact immunizations have had on reducing infectious disease and mortality rates—not even antibiotics (Alberta Health, 2007: 3).

Alberta's guide stated the need for ongoing immunization to overcome recent outbreaks. It presented itself implementing one of the best immunization programs in the country (Alberta Health, 2007: 3). Similarly, the Canadian Immunization Guide contextualized the vaccine narrative as an ongoing story in which vaccines continue to rid the world of disease: "Eradication of smallpox has been achieved. Currently, global efforts are directed at the eradication of polio and the elimination of measles. Ongoing immunization programs with high vaccine coverage are

needed" (PHAC, 2006a: 3). In this excerpt, the eradication of more diseases was depicted as an inevitable outcome of vaccine uptake and progress.

Even so, a UNICEF report from 2013 ranked the country's immunization rate 28<sup>th</sup> out of 29 countries (Crompton, 2015: 1; UNICEF, 2013: 14). In fact, UNICEF reported that Canada was only one of three countries that ranked below 90% vaccine coverage for measles, polio, and DTaP (diphtheria, pertussis, and tetanus) for children between twelve and twenty-three months old (Crompton, 2015: 1; UNICEF, 2013: 14). Vaccination programs are necessary to prevent disease outbreaks until diseases are globally eradicated because diseases travel across national borders (Crompton, 2015: 4). Across Canada, provincial governments have covered most of the financial burden of routine childhood vaccines. Despite efforts to make vaccination accessible, outbreaks of various diseases have occurred in various communities where vaccinations for them were available. These outbreaks occur most readily in communities with lower vaccination rates, which suggests that barriers to vaccination continue to exist even when parents can access vaccines for free (Crompton, 2015).

In Canada, the Public Health Agency of Canada has created immunization guidelines to improve these rates. The primary document is the *National Immunization Strategy*, which it created in 2003 (Crompton, 2015: 7). Provincial and territorial governments have been delivering and administering vaccines, which fall within their broader responsibilities pertaining to public healthcare (Crompton, 2007: 7; Mah, 2009: 23). Government guidelines have centered ideas about how to raise vaccine rates on assumptions about health professionals' knowledge and support of national immunization goals. For instance, the *Alberta Immunization Strategy* (2007) implied that health providers are responsible to educate new health professionals about vaccination and to provide information to patients and parents (Alberta Health, 2007, p. 9).

Vaccination policy has emphasized patient and parental education in ways that prioritize parental and individual choice. As such, individual security from unwanted interventions is prioritized over population health (Mah, 2009). In Alberta and most other provinces, it is easy for parents to opt out of vaccinating their children, and adults do not require any exemption to refuse immunization. Moreover, vaccination records can be incomplete. Alberta's Health Minister, Sarah Hoffman, stated that about fifteen to twenty-five percent of school-age children have missing vaccination records (Canadian Press, 2016). Ontario, Manitoba, and New Brunswick require proof of vaccination or valid exemptions prior to school entry (Picard, 2016; Ogbogu, 2014: 10). Rather than enforce mandatory vaccination, Alberta has implemented a policy to permit health officials to view school enrolment lists, so that they can contact parents of undervaccinated children (Canadian Press, 2016). As such, many Albertan parents seek non-medical exemptions specific vaccines or all vaccines for a variety of reasons, including conceptions of risk (Casiday, 2007; Crompton, 2015: 3; Keane et al., 2005). Decisions about whether to vaccinate, however, may have population-wide implications and cause disease outbreaks.

Most parents who adamantly oppose vaccination carefully weigh the consequences, uncertainties, and benefits that they believe result from vaccination (Hobson-West, 2007; Poltorak, Leach, Fairhead, and Cassell, 2005; Reich, 2014; Skea, Entwistle, Watt, and Russell, 2008). These parents have reserved doubts regarding the carefully calculated risks and benefits that many public health agencies presented to parents at the time of childhood vaccination appointments (Hobson-West, 2003, 2007). For instance, these parents expressed concerns about the relevance of this information for their individual child(ren). They also utilize various

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<sup>&</sup>lt;sup>1</sup> Provincial vaccination policies have other strengths and weaknesses that impact access to vaccination. For example, Manitoba lacks the "public health-delivered immunization clinics" that British Columbia offered "prior to or at the time of school entry" (Crompton, 2015: 76). These differences could present challenges to implementing mandatory vaccination policies.

resources about health—some of which are based in pseudo-science, and distrust information that they perceive to emerge from pharmaceutically funded research (Hobson-West, 2003, 2007; Poltorak, Leach, Fairhead, and Cassell, 2005; Reich, 2014). Parents who have actively refused to vaccinate their children often have researched more about immunization than the majority who passively comply with government recommendations (see Reich, 2014).

Much of the existing literature offered insights that primarily focus on the decisions that parents, and especially, mothers make regarding vaccination (Hobson-West, 2003, 2007; Keane et al., 2005; Poltorak et al., 2005; Reich, 2014; Skea et al., 2008). Nonetheless, some studies found health professionals (especially family physicians) were the primary information sources parents use when making vaccination decisions (Leask, Chapman, Hawe, and Burgess, 2006: 7238, 7241). Some authors argued that parental confidence in vaccination is high (Keane et al., 2005: 2492). Others added many parents somewhat distrust health information and want health professionals to provide more information regarding vaccination (Cassell et al., 2006: 788; Petts and Niemeyer, 2004: 11).

Many of the decisions that parents make are based in their own knowledge, which is created, maintained, and transformed through narrative accounts of vaccination. Studying these narrative accounts of knowledge, Andrea Kitta (2011) and Jacob Heller (2008) delved into the role of narrative in popular understandings of vaccination. In addition, many sociologists in recent decades have focused on narrative to understand the role of narrative structure in personal accounts, to empower research participants, and to acknowledge contradictory human experiences (Bloom, 1998; Roberts, 2002: 4; Smith and Watson, 2010; Swindells, 1995: 2). Personal stories also have gained interest among the public and social scientists (Miller, 2000: 73). As such, narrative plays a crucial role in popular understandings of vaccination (Heller,

2008; Kitta, 2011). Even so, most of studies that analyzed narratives about vaccination focused on popular and patient understandings (see Heller, 2008; Kitta, 2014; Poltorak, Leach, Fairhead, and Cassell, 2005).

In this dissertation, I investigated vaccine anxieties by embracing the narrative turn in sociological research and addressing the concerns of health professionals who are better educated than many patients and parents about vaccination, even though they specialize in areas other than vaccination. In particular, I analyzed how knowledge about vaccines emerged in narrative, how professionals use narrative to explain their own uncertainties, and how they critiqued the use of narrative in popular understandings of vaccination. I conducted qualitative interviews with physicians and nurses, which I analyzed to identify the role of stories and emotions in how interviewees explained their uncertainties and their role in the vaccine narrative. I explored how health professionals explained vaccines from their social position between experts and the public in a province that expects them to confidently relay vaccine information to patients. I wrote about this narrative in relation to all the narratives about vaccinations that the health professionals I interviewed discussed (adult and childhood). Many interviewees focused on childhood vaccines, which are the focus of much of the literature that I discussed in this dissertation. Below, I describe the context of Alberta, academic perspectives of vaccine knowledge and risks, and then provide an overview the content of this dissertation.

### Vaccination and anxiety in Alberta and Canada

In March 2015, news coverage about a measles outbreak in Disneyland and images of Disney characters covered in pox marks spread across Canadian and American media. In 2015, 189

Americans contracted the virus, but other recent larger outbreaks received less media attention (CDC, 2016b). For example, in 2014, there were twenty-three measles outbreaks and 667 cases

of measles in the US, many of which were connected to a large outbreak in the Philippines, and one of which included one outbreak of 383 cases of measles in an Amish community (CDC, 2016b). The outbreak in Disneyland, however, likely garnered international attention because of how easily the virus could spread from that tourist location. By March 11 in 2015, the virus had spread to Montreal and spiked to 119 cases (Janus, 2015).

In Canada, most vaccine-preventable diseases peaked prior to 1955 (PHAC, 2006a).

Nonetheless, some diseases have continued to resurge. For example, whooping cough outbreaks have been common in Canada with annual cases ranging from 695 to 4,540 between 2002-2012 (Crompton, 2015: 100). Although this is a very large number of cases, the drop from the 19,878 cases in one of the peak years (1938-1942) before the pertussis vaccine was authorized (1943) suggests that improved vaccine technology and uptake could diminish or eliminate this problem (Crompton, 2015: 100; PHAC, 2006a: "Index"). Likewise, during 2014, Canada's Public Health officials warned about measles spreading to Canada the thousands of cases in the Philippines and the Netherlands (Kershaw et al., 2014; Nursell, 2015). That year, measles outbreaks occurred in Alberta, British Columbia, Manitoba, Saskatchewan, and Ontario (Crompton, 2015: 11; Franklin, 2015; Mertz, 2015; PHAC, 2014). Notably, a religious community in British Columbia's Fraser valley experienced an outbreak of 456 measles cases (Crompton, 2015: 41; Kershaw et al., 2014). Recent measles outbreaks alerted provincial governments to the need to maintain vaccine uptake rates because of the movement of disease across national borders.

#### Vaccine ambivalence and uptake

Efforts to measure herd immunity levels have failed to capture all missed vaccinations. Even so, Canada immunization rates have fallen below national targets (Crompton, 2015: 10).

Immunization rates vary across Canada different reasons. For example, higher income parents

have been the most likely to *decide* to under-vaccinate their children due to their ambivalence and perceptions of vaccine-related risks (Crompton, 2015: 12; Heller, 2008: 15; Reich, 2014). Refusal of vaccination due to such ambivalence may explain fluctuations in vaccine uptake rates, but it inadequately explains average uptake rates. Specifically, Alberta's vaccine uptake rates have been positively correlated to income level (Alberta Health, 2015b), which suggests that access could remain an issue for some parents. Nevertheless, unvaccinated children have often lived in communities with lower vaccination rates and fluctuations contributed to the spread of disease.

Notably, a survey of Canadian parents demonstrated substantial gaps in vaccine knowledge (Ritvo et al., 2003). For example, over thirty percent and over fifty percent of participants responded to two questions about vaccine safety in ways that implied they thought vaccines were unsafe or that they lacked enough information to comment on the safety (Ritvo et al., 2003: 5). More recently, a 2011 Public Health Agency of Canada survey suggested that about 50% of parents believe that newer vaccines to be less safe than older vaccines (EKOS, 2011: iv; see also Crompton, 2015: 15). Given the prevalence of scepticism in public vaccine knowledge, it is unsurprising that most provinces have struggled to maintain current vaccine rates, which are well below national targets.

Many communities have refused vaccines at higher rates than others, but some faced greater access issues (Crompton, 2015: 55). UNICEF estimated that immunization rates are 20% below Canada's national average for indigenous children (Crompton, 2015: 28; Eni, 2009: 8). The vaccination of such populations as indigenous peoples, new immigrants, and refugees fall between federal and provincial/territorial responsibilities, and as such, their needs can be overlooked (Mah, 2009: 23). Children in rural communities and lower income children also tend

to be under-vaccinated (Crompton, 2015: 12, 41; Mah, 2015). Moreover, some regions of Canada have struggled to keep up with population growth, some people lack a regular family doctor, and some larger families may have found traveling to health clinics challenging (Crompton, 2015: 32, 41). It is difficult to find precise numbers about vaccine uptake rates because of challenges with Canada's existing immunization registry and to identify the individuals' immunization status because of missing information (Crompton, 2015: 33). In 2013, estimates suggest that only 2-3% of Canadian children were completely unvaccinated, but only 60-73% of children were up to date with every recommended vaccination (Crompton, 2015: 11, 35, 56). Of all the Canadian provinces, only New Brunswick and Ontario have required proof of vaccination prior to school entry in recent years, but both allow for certain exemptions (Crompton, 2015; CBC, 2015b).

# The Province of Alberta

Vaccination rates in Canada vary in accordance with provincial vaccination policies, within the specific demographic context of each province. When I collected data for this project, Alberta's resource-based economy was strong and its population was relatively diverse compared to other provinces. In 2011, and Alberta had the highest employment rates and the median family income (\$80,271) was 20% higher than the national average (Alberta Treasury, 2013b: 1; Alberta Treasury, 2013c: 2). Compared to the national average of over 60%, over 69% of Albertans over fifteen years old had some form of employment (Alberta Treasury, 2013b: 1). Even so, Alberta had the highest wage gap based on gender in the country (Alberta Treasury, 2013c: 3). Between 2015 and 2017, the employment rate likely declined because oil prices, which support the economy, have been in flux.

Compared to other provinces, Alberta has a relatively young population (average 36.1 years old), with relatively high household incomes, and high rates of home ownership (Alberta Treasury, 2013c: 1). About 18% of Alberta's population identified as visible minorities (Alberta Treasury, 2013a: 2). Likewise, about 18% of Alberta's population were first-generation immigrants, 84% of who have settled in urban regions (Alberta Treasury, 2013a: 1). Conversely, Alberta's rural communities have aged, struggled to recruit immigrants, and their per capita income was well below urban averages (Arcand, 2012: 13-14, 41).

In Alberta, Public Health nurses have provided vaccines and vaccine information at Public Health offices and school settings (Matkin, Simmonds, and Suttorp, 2014). There are benefits and challenges associated with this approach. For instance, Public Health nurses have provided consistent vaccine information and delivery to parents (Crompton, 2015: 32). As such, some physicians may have prioritized other issues over vaccination during "well baby care" appointments, which have been an opportune moment to address parents' vaccine concerns and potentially to vaccinate babies (Crompton, 2015: 32). Furthermore, some parents hold physicians' perspectives in higher regard than nurses regardless of the quality and breadth of Public Health nurses' knowledge (Leask et al., 2006: 7238, 7241).

Vaccine uptake was lower than the rates that the province deems necessary to sustain herd immunity—although this varied greatly with each vaccine. In Alberta, vaccine coverage ranged from almost 7% to over 11% below national targets for different vaccines (Crompton, 2015: 11). A nurse who researches vaccine trends in Alberta estimated that 10% to 20% of Alberta children are incompletely immunized (MacDonald interview in Southwick, 2009). Parts of southern Alberta had dramatically low vaccination rates for specific vaccines. For instance, in 2013, only 64% to 76% of children in the area surrounding Lethbridge received the MMR vaccine

(Crompton, 2015: 37). In southern Alberta, many refusals occurred in relation to parents' religious beliefs or cultural norms (Crompton, 2015: 36). Even so, the community of High Level, in Northern Alberta, had the lowest uptake rates in the province of 61% for the first dose of DTaP-Hib (diphtheria, tetanus, accelular pertussis-polio, and haemophilus influenza), and 32% for the forth dose (Crompton, 2015: 37). Likewise, only 50% of children under two in that community received the first dose of the MMR (measles, mumps, and rubella) vaccine (Crompton, 2015: 37). Even so, the Alberta Immunization Strategy boasts about the strength of its comprehensive coverage (Alberta Health, 2007: 3).

Furthermore, the HPV vaccine has remained controversial, especially because the province first only covered its cost for girls. Provincial estimates suggested that uptake rates for that vaccine have remained well below 70% between 2010 and 2015 in Alberta (Government of Alberta, 2016). In fall 2014, Alberta extended its HPV (human papillomavirus) program to cover boys as well as girls.

Outbreaks of other diseases have occurred in recent years and were relevant to this dissertation (see Government of Canada, 2015). I focused, however, on the example of measles uptake because Alberta's recent experiences with that disease provided a potent example of an issue that was easiest to understand on a case-by-case basis. Measles is highly contagious. As such, Alberta's target rate for the MMR vaccine has been 98% for the first dose (before two years of age) and 99% for the second dose (before seven years of age [Matkin, Simmonds, and Suttorp, 2014]).

In Alberta, reports of uptake rates have varied between government publications and regions. Pockets of Alberta have MMR immunization rates over 90%, but none attained the target of over 98% (Crompton, 2015: 37). By the time I conducted my interviews, uptake rates had dropped

from the years before. One government report stated that provincial rates for the first dose of the measles vaccine dropped to 85.7% for children under two-years-old (Alberta Health, 2015a). Matkin, Simmonds, and Suttorp (2014) found that 42.8% of children under two-years-old in southern Alberta had not received the first dose of their measles vaccine as of June 2013. They found rates of children over seven-years-old who were fully vaccinated ranged from 55% to 90% in Alberta and averaged 77.6% of children under (Matkin, Simmonds, and Suttorp, 2014). Areas where vaccination rates were well below the surrounding communities included schools, particularly private schools that supported certain religious/cultural backgrounds (Matkin, Simmonds, and Suttorp, 2014).

Alberta experienced an outbreak of 44 cases of measles between October and November of 2013 (Alberta Health, 2015a). Of those cases 86% were unimmunized, 13% had an unknown immunization history, and all were from ten households (Crompton, 2015: 41; Kershaw et al., 2014). Then, in spring 2014, a second outbreak spread throughout the province (Alberta Health, 2015a). Cases in Edmonton, Calgary, and southern Alberta received most media attention.

In response to these outbreaks, news coverage and policy appeared to emphasize parental uncertainties, ambivalence, and opposition to vaccination. Indeed, policy and talk about vaccination often emphasized choice, which implied individual protection from compulsory immunization, rather than communal protection from disease outbreaks (Mah, 2009). Such talk emphasized the importance of protecting oneself and others from infectious diseases by deciding to vaccinate.<sup>2</sup> This talk focused on parental decision making without acknowledging broader issues in healthcare. Issues around vaccination access and dissemination are integral to raising

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<sup>&</sup>lt;sup>2</sup> Prominent examples of this emphasis on choice can be observed in many immunization advertisements. For instance, influenza vaccination advertisements at the University of Alberta have often featured a young person posing in armor with such statements as, "Knights of the vaccine: valiant fighters of influenza" (University of Alberta, 2016).

uptake rates, but issues around vaccine uncertainties and ambivalence included those experienced by healthcare providers as well as parents and patients.

# Vaccination knowledge and uncertainties

Most previous literature about vaccine uncertainties addressed the role of anti-vaccination organizations or methods to increase uptake rates. Many researchers have investigated topics relating to various conceptualizations of vaccine knowledge and risk involving primarily patient (and occasionally health professional) uncertainties, noncompliance, and resistance (see Casiday, 2007; Hobson-West 2003, 2007; Leach and Fairhead, 2007; Levi, 2007; Poltorak, Leach, Fairhead, and Cassell, 2005; Skea, Entwistle, Watt, and Russell, 2008; Streefland, Chowdhury, and Ramos-Jimenez, 1999; Wolfe and Sharp, 2002). Sociological inquiry into contemporary vaccine knowledge and uptake and use has relied on the heavily theorized concept of risk.

In sociological research, *risk* can be used to represent either measureable or unmeasured/immeasurable outcomes (Beck, 1992; Gigerenzer, 2003: 26; Hobson-West, 2003). Some social scientists have used the term "risk" to explain perceptions of risk (Douglas and Wildavsky, 1982). I have followed Gerd Gigerenzer (2003) by using risk to represent measured outcomes unless I stated, "unknown risks" or "perceived risks." As Melissa Leach and James Fairhead (2007) explained, "A genuine situation of risk prevails where there are calculable probabilities between known outcomes." Similarly, Mark Ritter wrote in the "Forward" for Ulrich Beck (1992): "Risks are defined as the probabilities of physical harm due to given technological or other processes" (p. 4). As such, risks can be measured through the production of *knowledge*, which can be formal or informal.

Knowledge can refer not only to content, but also the forms and practices of knowing (Swidler and Arditi, 1994: 307), which include formal (and professional) knowledge as well as

informal (and lay) knowledge. Knowledge creates *uncertainty* (Gerrity et al., 2003), which denotes gaps in scientific knowledge, professional training, and/or the practices of knowing (Fox, 2000). I have used *uncertainty* to denote both widely recognized gaps in knowledge and individuals' perceptions of the unknown, which often exist as part of knowledge (see Fox, 2000).<sup>3</sup>

Anxieties can emerge from both risks and uncertainties. Melissa Leach and James Fairhead (2007) argue, "Anxiety connotes active engagement with an uncertain world, recognizing a grappling creativity," and the term has more accurately represented the current controversies about vaccines than risk (p. 168). Anxieties involve reactions and reflection about vaccine safety. They can lead to an increased acceptance of vaccines when anxieties include the possibility of disease outbreaks (Leach and Fairhead, 2007: 3). Other scholars have used these terms to hold slightly different meanings. For instance, Atkinson (1984) critiqued Fox's (2000) inclusion of uncertainties that lack doubt in her understanding of "uncertainty." Each of these terms have factored into understandings of various healthcare treatments, but all can appear in narratives about vaccines and all can resonate with emotions.

In addition, scholars have argued about the ongoing "democratization of knowledge." Some argued that strong valuations of patient opinions and beliefs—which they referred to as "lay knowledge," "experiential knowledge," or "lay expertise"—could empower patients who would otherwise experience medicine as a paternal force (Arksey, 1994; Blume, 2017; Kerr, Cunningham-Burley, and Tutton, 2007; see Prior, 200342-45). In fact, some scholars have extended lay knowledge to refer to specific disciplines into which patients may offer insights

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<sup>&</sup>lt;sup>3</sup> My use of uncertainties differs from Leach and Fairhead (2007) who stated that uncertainty involves possible known outcomes, but "no credible basis for assigning probabilities to them" (p. 27). Specifically, unlike Leach and Fairhead (2007) I have allotted "ambiguity and ignorance" into the category of "uncertainty" (p. 27).

often without specifying any differences between "lay" and "expert." For example, some scholars used the term "lay epidemiology" (Davison, Smith, and Frankel, 1991; MacDonald, Graham, and MacLeod, 2015). Prior (2003) stated that this expansion of expertize recreated "lay people" as "multi-skilled and knowledgeable individuals," but that many scholars have failed to specify whether patients' expertise rests in experience or scientific knowledge (p. 44-45).

Scholars such as Prior (2003) expressed concern that ever-expanding notions of expertise restrict professionals' ability to help patients or over-embellish the role of uncertainty in widely understood treatments. Indeed, the roles of "lay knowledge" and increasing awareness of medical uncertainty could counter health professionals' legitimacy and intellectual dominance over their respective areas (Hobson-West, 2007: 211; Lankshear, Ettorre, and Mason, 2005: 362; Prior, 2003: 43; Leach and Fairhead, 2007: 4; Streefland, Chowdhury, and Ramos-Jimenez, 1999: 1712). Some scholars have called non-experts (often including patients) "lay experts" without specifying what legitimizes lay people as experts (Prior, 2003: 45).

Some non-experts, especially those with extensive experience in an area that has fallen under investigation, could offer invaluable contributions to understanding a phenomenon that scientists may otherwise overlook (Collins and Evans, 2002: 256). Indeed, Blume (2017) critique that *how* lay understandings come to be deemed as "knowledge" rather than whether those understandings, could carry value in informing personal choice and patient participation (p. 100). The boundaries between valuable lay-perspectives and expertise overlap, but these boundaries have involved different forms of contributions to knowledge (Collins and Evans, 2002: 251). In many instances, the inclusion of lay perspectives can improve care, such as with the delivery of HIV/AIDS treatments (Kerr, 2007: 386). Indeed, Andrea Kerr (2007) critiqued Collins and Evans (2002) and Prior's (2002) articles, which argued that the public has played too great a role

in how science is organized and applied (p. 386). Even so, Stuart Blume (2017) expanded upon critiques of the use of "experiential knowledge" by reflecting on the transformation of patients into supposedly empowered healthcare consumers more so than knowledgeable individuals (p. 92). Blume (2017) questions the meaning of the term "experiential knowledge" in relation to the variety of forms of knowing that exist and the ability to transmit that knowledge (i.e., how to ride a bike, senses of morality, and scientific rationale [p. 94]).

While I agreed that experts can be wrong and that public perspectives have been relevant to aspects of medical and scientific endeavours, I have aligned more closely with Prior's (2002) assessments and Blume's (2017) assertions that generally, experience is "worthy of being characterized as 'knowledge' only to the extent that it appears compatible with medical knowledge and assumptions" (p. 99). By definition, "lay experts" are non-experts even though some people who lack credentials have influential opinions. Dictionary definitions have implied the term is an oxymoron—layman means not an expert (Collins and Evans, 2002: 238; Prior, 2003: 53; see Blume, 2017: 99). Such a designation is dangerous in that "even the most respected vaccine authority's advice becomes just another opinion" (Kata, 2010: 1715).

For instance, Lindsay Prior (2003) argued that Andrew Wakefield and colleagues (1998) relied on lay knowledge in their article that erroneously linked autism to the MMR vaccine in a scientific article (Prior, 2003: 51). Wakefield created what appeared to be legitimate evidence of risk because of his credentials as a physician and his publication of a scientific article in a respected medical journal (Prior, 2003: 52). Prior (2003) insisted Wakefield had overstepped his professional bounds and was no more than a "lay expert" in the field of his now retracted article. Nonetheless, public narratives perpetuated the influence of Wakefield's findings, such that some parents have continued questioning the safety of the MMR vaccine. Although Prior (2003) said

Wakefield was a "lay expert," I argue his knowledge rested between experts and the public. Wakefield should have general knowledge of many health issues beyond what the public knows, but his training as a gastroenterologist and medical researcher should have prepared him to recognize and remain within his scope of practice.

Publicly disseminated vaccine anxieties have received especial attention from scholars in the arts and health science scholars. Several academics analyzed the content of anti-vaccination websites (Bean, 2011; Hobson-West, 2007; Kata, 2010; Wolfe and Sharp, 2002). The media and anti-vaccination discourses have played key roles in the creation of "lay knowledge," which appeared to impact public trust in practitioners and vaccination (Leask and Chapman, 2002: 446). Many forms of media have sensationalized adverse reactions to vaccines (Bean, 2011: 1875; see also Casiday, 2007: 1064; Hilton et al., 2010; Wolfe and Sharp, 2002: 431). Likewise, media coverage of disorders, such as autism overemphasized supposed environmental causes (including the MMR vaccine), but inadequately reported brain and behaviour research (Russell and Kelly, 2011). Media stories about vaccination risks overwhelmingly presented personal accounts of possible harm to children, which have appealed to readers' emotions with stories that are easy to interpret (Hilton et al., 2010; Leask and Chapman, 2002). Conversely, vaccine supportive scientific and medical literature traditionally received limited characterless media attention that often dismissed the very real concerns that parents have regarding vaccine safety (Hilton et al., 2010: 944; Leask and Chapman, 2002; Mnookin, 2011: 114).<sup>5</sup>

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<sup>&</sup>lt;sup>4</sup> Even sociological inquiry into this topic increased following media coverage of the MMR controversy (Hobson-West, 2007: 198).

<sup>&</sup>lt;sup>5</sup> Leask and Chapman (2002) analyzed the portrayal of pro-vaccination advocates in Australian newspaper articles from the 1990s. They found that accounts promoting vaccination were less personal and less sensational than those in opposition. Although Leask and Chapman (2002) found few Australian news stories promoted anti-vaccination claims, those claims were "located under a canopy of more general newsworthy discourses about cover-up and conspiracy,"

Some researchers asserted that patients often independently research websites, of which antivaccination sites appear most readily in an online search (Bean, 2011; Kata, 2010). Other researchers suggested that the internet is used less than other information sources—including news reports or information from health professionals—but that information from all sources has dispersed through social networks, social media, and other formats as well (Cassell et al., 2006: 788; Petts and Niemeyer, 2004). Moreover, some Complementary and Alternative Medicines (CAM)—such as homeopathy, naturopathy, and chiropractic—have fallen under scrutiny because some of their practitioners have voiced opposition to vaccination (Busse, Wilson, and Campbell, 2008; Campbell, Busse, and Injeyan, 2000; CBC, 2014; Ernst, 2002; Russell et al., 2004). Practitioners from numerous types of CAM have opposed vaccination (Ernst, 2002: S92).

Despite the emphasis on non-medical information sources and vaccine opposition, some studies found parents primarily rely upon health professionals (especially family physicians) when making vaccination decisions (Leask, Chapman, Hawe, and Burgess, 2006: 7238, 7241). Health professionals' views greatly affected patient decisions: "Several studies have shown that physician knowledge of immunizations and contraindications to immunizations can affect vaccine uptake among their patients" (Gust, et al., 2008: 574). Furthermore, vaccine ambivalence and uncertainty appeared to be more prevalent among patients than anti-vaccine sentiments (Blume, 2006; Poltorak, Leach, Fairhead, and Cassell, 2005: 716).

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manipulation of private enterprise interests, governments with totalitarian agenda and the back-to-nature idyll" (Leask and Chapman, 2002: 446).

<sup>&</sup>lt;sup>6</sup> CAM training programs have also received inquiry. For instance, Jason Busse, Kumanan Wilson, and James Campbell (2008) found that formally, the Canadian Naturopathic Association (CNA) and the Canadian Chiropractic Association (CCA) stated no opposition to vaccination (Busse, Wilson, and Campbell, 2008: 6238-6239). Nonetheless, these authors found that both organizations had substantial informal education components that students granted a great deal of legitimacy and that opposed vaccination (Busse, Wilson, and Campbell, 2008).

Even so, health professionals who have shared vaccine knowledge with patients may have lacked accurate information or fallen short of effective communication. Stuart Blume (2006) argued that according to many parents: "Professionals seem frequently to have been seen as an obstacle to informed choice, rather than a source of advice and information" (p. 637). He argued that the information that professionals provided was not designed to inform, but to induce conformity or normalize (Blume, 2006: 637). Some physicians dismissed parents' concerns as ignorant and/or confrontational (Levi, 2007: 23). Other physicians disrespected parents' decisions to leave their children unvaccinated: "Significant numbers of physicians hold that failure to immunize is tantamount to child abuse" (Levi, 2007: 23).

Research in the United Kingdom suggested that parental beliefs play an increasing role in vaccine uptake (Smailbegovic, Laing, and Bedford, 2003: 304). Nevertheless, most worried parents are confused about whom to believe and about potential downsides of immunization (Levi, 2007: 23). Physicians' responses to parental concerns influence vaccination decisions, but they often divert parents to internet research, which has tended to favour anti-vaccination (Levi, 2007: 23). Several United Kingdom physicians in Mike Poltorak and colleagues' (2005) study encouraged parents to conduct personal research (p. 714). They found that some physicians did not counter patients' previously held vaccine beliefs. These physicians stated that most patients sought support for their stance on vaccination, rather than advice (Poltorak, Leach, Fairhead, and Cassell, 2005: 715). Likewise, many of the mothers in their study confirmed these suspicions by seeking out like-minded health professionals who were often CAM practitioners (Poltorak, Leach, Fairhead, and Cassell, 2005: 715).

Although research about health professionals' interactions with patients is growing, less research is available about health professionals' vaccine knowledge. For example, Julie

Crompton (2015) interviewed nine Canadian vaccine experts and stakeholders including program managers, clinician researchers, and Public Health experts (p. 19). She found that many stakeholders alleged that parents' beliefs, attitudes, and misinformation were a primary reason for refusing to vaccinate their children. Notably, however, stakeholders identified physicians' perspectives of vaccines to be problematic because some physicians recommended alternative vaccine schedules or lacked information themselves (Crompton, 2015: 31). Other research has addressed nurses' vaccine ambivalence, but investigations into physicians' ambivalence are rare (with the notable exception of Maryna Bazylevych's [2011] article based in the Ukraine and select medical research [see Dubé et al., 2011: 3178-3179; Levi, 2007; Loulergue et al., 2009: 4242-4243]).

I began this research project with the exploratory question: 'How do healthcare professionals experience uncertainties (and, at times, apprehension) about medical knowledge when advising about vaccination?' As I progressed through this project, my research questions became: 'How do health professionals use narratives to convey confidence, uncertainty, and/or doubts in vaccines? What tactics do health professionals discuss as enhancing their confidence? What doubts do they share about specific vaccines?' In addressing these questions, I wrote about my methodological approach, historical and contemporary perspectives of vaccination, and four related chapters about vaccine anxieties, risks, and narratives.

### **Overview of Chapters**

Vaccine anxieties, in all forms, offer an opportunity to observe the operation of medical knowledge and practice:

Vaccination anxieties are a lens for understanding how biomedical knowledge is interpreted on the ground. Health risks are constructed not only in biological terms but

also as a product of relationships among the state, providers, patients, and international health policy makers (Bazylevych, 2011: 451-452; see also Chen, 2005 and Kitta, 2012). The relationships among diverse actors in vaccination dissemination have been as prevalent in Canada as other parts of the world. Moreover, narratives are implicit in how biomedical knowledge is used and how health risks are constructed within these relationships. They are particularly useful in the understanding and transmission of information about vaccines (Heller, 2008; Kitta, 2012). Nevertheless, the role of narratives in vaccine knowledge and health professionals' knowledge is under-researched. Furthermore, health professionals' management, experience, and narratives about these vaccination uncertainties are virtually unaddressed (Kitta's 2012 book offered some insight into this issue, but focused on all forms of narrative and speakers about vaccination).

I investigate how health professionals expressed their uncertainties by following the narrative turn in sociology, which I discussed in Chapter Two. To gather professional narratives about vaccination, I conducted semi-structured interviews with thirty-four physicians and nurses.

During interviews, I gathered short narratives about vaccination, which I found centered on four separate, but related topics. In addition, I reviewed literature about events that preceded contemporary anxieties about immunization in Chapter Three. In that chapter, I address how vaccine anxieties, uncertainties, and narratives influenced healthcare decision making from the advent of the smallpox inoculation until recent perceptions of the measles vaccine.

The remaining chapters present findings from my analysis of the interviews I conducted. In Chapter Four, I address health professionals' accounts of the potential risks associated with vaccination. In particular, I delve into perceptions of the influence that government and pharmaceutical companies have on vaccine schedules and safety. To address these topics, I

utilized theories of risk, safety, and pharmaceuticalization to analyze the ways in which health professionals presented their personal anxieties about vaccination and vaccine information.

In Chapter Five, I analyze how health professionals managed their own uncertainties in ways that allowed them to support the culturally dominant narrative that suggests vaccination is the safest and best way to maintain health. In particular, I address how professionals supported vaccination as a general health measure while acknowledging varying degrees of personal uncertainty. Uncertainties included anything from gaps in patients' vaccine records to acknowledgements that certain vaccines could have side effects or be less effective than once hoped.

The topics in Chapter Five spurred my interest in how health professionals present themselves while acknowledging personal uncertainties. I investigate these issues in Chapter Six. I use Judith Butler's (2005) book *Giving an Account of Oneself* to discuss the professional accounts of oneself that emerged during interviews. Particularly, health professionals provided me with an account from a social position between vaccine experts and the wider public. I detail how professional accounts of knowledge, the limitations of knowledge, and the "others" who know less operate in ways that maintained professional status and legitimacy.

Finally, in Chapter Seven, I explain how professionals presented widespread emotional responses of vaccine risks and uncertainties, such as fear. Narratives communicate information in ways that make information palpable partly because they engage human emotions. Health professionals expressed concerns about the role of media, social networks, and celebrity endorsement in public conceptions and fears of vaccines. I pay particular attention to health professionals' accounts for the numerous actors and competing narratives that shape understandings of vaccination.

In the Conclusion, I discuss how these chapters are inter-related. Then, I question whether vaccination education programs that focus on patient choice are an adequate response to variable vaccine uptake rates in our risk-obsessed culture. I propose that there is a need to expand the way we think about medical uncertainties. Particularly, I suggest that focusing on individual patient education and local contexts may be problematic in a culture that is increasingly attuned to issues of risk and uncertainty.

## **Chapter Two**

# Researching health professionals' vaccine narratives and accounts

Medical knowledge has been the focus of many social scientists' critiques. This dissertation has continued that tradition of questioning and critique, but in a somewhat uncommon way. Rather than investigating doubt and health practices that accompany scientifically recognized risks, I questioned the inevitable role of minor uncertainties with a widely accepted preventative treatment. In other words, I analyzed the mundane uncertainties that accompany a basic health procedure. To pursue this topic, I sought out vaccine narratives and conversations with health professionals in the form of semi-structured interviews. Often, the stories that emerged during interviews were brief, but they provided snapshots about health professionals' experiences with immunizations and vaccine anxieties. These snapshots offered opportunities to observe issues relating to the operation of medical knowledge and practice (Bazylevych, 2011: 451-452). Moreover, these narratives constituted accounts that interviewees used persuasively to evidence their medical expertise. I analyzed interviews in relation to dominant cultural narratives about vaccines, healthcare professionals' personal use of narratives to create an account of their professional role, and their understanding of how narratives influenced their practice.<sup>7</sup>

The following describes my methodology and journey through this project. I begin by reflecting on the initial development and planning of this research topic. Second, I discuss

<sup>&</sup>lt;sup>7</sup>Although I focused on healthcare professionals' uncertainties, I expected some professionals to discuss various sources of apprehension, including patient uncertainty. These sources relate to my project because of their influence on practice. For instance, patient uncertainty could manifest in uncertainty regarding counseling skills, which are integral to medical practice. For primary care providers, "soft skills" (including counseling, professionalism, communication, and so forth) are necessary for any effective implementation of medical knowledge (see Epstein and Hundert, 2002). Poor communication skills could compromise one's ability to treat patients who may refuse or passively comply with recommendations due to a lack of understanding, feeling disrespected, or other reasons.

narrative analysis and how I crafted it to fit this project. Third, I overview my initial failure to recruit participants and how I adapted my research plan. Forth, I discuss the interview process. Fifth, I examine how my project took shape during the implementation of these procedures. Finally, I provide a demographic overview of the health professionals who I interviewed.

## Why vaccine uncertainties?

Vaccine narratives circulate throughout healthcare environments and other public encounters.

As I waited in a clinic to conduct an interview that I scheduled with a physician, I overheard a common conversation:

'Do you believe in those [vaccines]?' said one woman to the clinic administrative staff who was questioning a young couple about their infant. 'Yes,' the staff said, then she disengaged from the commentary that followed. The woman detailed how her niece reacted to her last vaccine. She said that the child cried incessantly and became ill. The young couple continued to wait without verbally acknowledging the woman's concerns. Vaccines slipped from the conversation and the assault on vaccine safety skidded by with unknown impact (Fieldnotes, May 6<sup>th</sup>, 2014).

Throughout this project, I heard countless stories about immunization that I excluded from my analysis. Everyone has experience with vaccines or with some form of illness (albeit, sometimes common diseases, such as influenza or a common cold). With these common experiences, people voice concerns that become public narratives. Vaccines take on a narrative life through which people express underlying concerns, beliefs, and values about preventative medicine, informed consent, and population health (see Kitta, 2012).

### **Initial Planning**

My understanding of healthcare is that the application of medical science to the human body is imprecise and rife with uncertainties (see Gigerenzer, 2003; Knight and Mattick, 2006). In my own words: "Once in practice, medicine is a scientifically informed human art" (Fieldnotes,

October 11, 2013). As such, healthcare professionals rely on their experience and training in addition to scientific knowledge, which has become too vast for any one professional to completely master (see Fox, 2000). My own experiences with Alberta's medical system spoke to these issues:

Anti-vaccine campaigners are a small portion of the population who and likely do not cause all refusals (Poltorak et al., 2005: 716). Yet, they could represent wider problems with our healthcare system (Bazylevych, 2011: 451). In my own experience trying to manage relatively mild post-concussion symptoms, it can be quite difficult to get adequate information about issues that carry a large amount of uncertainty. Similar difficulty also could be the case for simpler procedures. Vaccines are so numerous and variable that I cannot imagine that any professional has the knowledge or time to address every potential concern (Fieldnotes, October 11, 2013).

From this perspective, and informed by previous literature, I sought to investigate healthcare professionals' narratives about the slight uncertainties and apprehensions that can accompany vaccines:

My own interest in uncertainty arose from the perception that if two extremes within medicine exist—such as vaccine champions and anti-vaccine supporters—then a middle ground exists. Finding this middle ground, however, is an intimidating endeavour that involves challenging perceptions of certainty (Fieldnotes, October 15, 2013).

While drafting my information sheet and interview guide, I anticipated many health professionals would view my topic as commonplace, but may participate due to either concerns about growing vaccine refusal or general support of scholarly research. I intended to interview as many health professionals as manageable regarding these issues. I decided upon narrative analysis because I hoped to investigate common vaccine narratives and stories about professionals' experiences. The challenge I faced was convincing health professionals to share time and stories about a procedure that most deemed very simple.

Narrative analysis was a guiding factor in my project design from the earliest stages. People often express vaccine beliefs as contemporary legends, personal narrative, or some combination of these (Kitta, 2012: 21). Through narratives, vaccines have achieved an important role in American culture (Heller, 2008)—and likewise, Canadian culture. The opening lines of the Alberta Immunization Strategy referenced the dominant cultural vaccine narrative by stating vaccines are "one of the greatest medical success stories in human history" (Alberta Health, 2007: 3). Narratives about vaccines also operate within health professions. Andrea Kitta (2012) found that health professionals use narratives to talk about their personal experiences, their colleagues, and their interactions with patients (p. 96). Furthermore, she explained that they might use contemporary legends (e.g. some healthcare professionals she interviewed "invoke the legendary motif that children can be taken away from their parents if they are not vaccinated" [Kitta, 2012: 97]).

Through this project, I sought diverse stories, common experiences, and perceptions of the dominant vaccine narrative. To address these topics, I sought a large sample of health professionals (in the end, thirty-four participants). I believe that the breadth of participants I interviewed offers a different type of richness than narrative traditions that follow three to four individuals' life stories. If my interviews were short, then I planned to recruit up to fifty participants and piece together common narratives and unique samples that demonstrate experiences with vaccine uncertainties. Alternatively, if interviewees offered a great deal of depth, then I would conduct as few as fifteen interviews and focus more on individual stories. Perhaps predictably, interviews fell between these extremes. As such, I have compiled this dissertation as a compromise between these extremes in my attempt to piece together support of

widespread cultural narratives, while providing longer excerpts and details from some participants.

# The logistics

# Recruitment failures and adaptation

Initially, I had ethics approval from the Research Ethics Board and Health Ethics Board at the University of Alberta to interview pediatricians and family physicians practicing in Alberta. Nevertheless, my early efforts proved futile. I began recruitment in fall 2013 and I scheduled three interviews through acquaintances and one through email. I almost had a fifth interview, but the participant withdrew. No one else responded. In December, I pursued further initiatives. First, I snowball sampled through acquaintances who had recently completed medical degrees. Second, I tried walking into clinics to disseminate information about my project. Third, I emailed some faculty physicians and found a small, but worthwhile, subset of participants.

Despite these efforts, the New Year passed and I still had only four participants. I felt defeated. I revisited research publications, which rarely detailed how they gained access to physicians. From reading studies and contacting a couple researchers, I found that recruitment success often rested in one's professional networks and local context. I sought advice from methodological articles, which were based in either different or broader contexts than Alberta's clinics. For instance, some studies first approached physicians through text (email or mailed letters [see Shah et al., 2014]), but I found such tactics extremely ineffective. Steven Asch and colleagues (2000) offered useful suggestions including using of incentives, relying on professional networks, recruiting through physicians, and minimizing the burden of one's study. Similarly, Shellie Ellis and colleagues (2007) gave useful information about the benefits of various recruitment strategies and the presentation of recruitment material. I lacked the

professional networks that all studies epitomized, and so I minimized the burden of the study by offering to meet over lunch and presented recruitment materials effectively (see recruitment letter and consent form in Appendix A and B). Nonetheless, my efforts continued to fail.

In addition, the clinics I visited often referred me to nurses who offered valuable insights. For example, one nurse described her daughter's anaphylactic reaction to a vaccine. She explained that the nurses who administered the vaccine panicked and failed to respond to the life-threatening situation. Then, she had to use her training as a nurse to save her daughter's life. Furthermore, a couple of acquaintances volunteered for my project whose specialties were outside family medicine and pediatrics. Consequently, I amended my ethics application to include nurses and all physician specialties.

In the process of developing new recruitment tactics, I contacted a pharmaceutical representative for advice because of the similarities between her career and my research. Her career involved convincing busy health professionals in Alberta to spend thirty to sixty minutes discussing pharmaceutical interventions. I found her advice insightful and relevant to the context of Alberta. In addition, she said that she met physicians who had unique practices with specific vaccines. For example, she informed me that one physician provided patients both Gardasil® (by Merck) and Cervarix<sup>TM</sup> (by GlaxoSmithKline) human papilloma virus (HPV) vaccines to individual patients. She explained that the doctor used this practice to accommodate the pros and cons associated with each vaccine.<sup>8</sup> As such, I emerged from this meeting optimistic that I would recruit more participants and would encounter a diversity of perspectives.

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<sup>&</sup>lt;sup>8</sup> The reasoning was to enhance protection against more strains of HPV for each patient, despite the lack of conclusive medical evidence for using both vaccines on one patient. Gardasil® is recommended by the Canadian government and it is a quadrivalent vaccine, which protects against four strains of HPV. Cervarix<sup>TM</sup> is a competitor vaccine that protects against two of the

## Recruitment

With the drug representative's advice and a research grant from the University of Alberta's Department of Sociology, I adapted my recruitment strategies to incorporate some of the tactics to which drug representatives have already familiarized clinic staff. Over the next four months, the number of physicians in my project jumped from four to twenty-six. Despite this jump, my tactics changed only subtly. I still dressed in business clothes, but now I asked to speak directly to physicians and I offered participants lunch using grant funding. I brought clinic staff treats, which the Rx&D code of Canada forbids pharmaceutical representatives from doing (Innovative Medicines, 2016: 32). In addition, I followed my friend's advice (and my experience) to avoid Medicentres<sup>9</sup> and most walk-in clinics because they are often much busier than other clinics.

With this improved recruitment came new challenges. First, I had to delay some participants' interviews because ethics processed slowly and I was awaiting approval to interview nurses and other specialists. I lost at least one participant as a result. After ethics approval, however, I actively recruited several public health nurses because many of the physicians I interviewed insisted that public health nurses were the primary vaccine experts. Second, often I was mistaken for a pharmaceutical representative. The ethical ramifications of this were immediately clear as I stood in a doctor's office holding lunch explaining that I would not be presenting a pharmaceutical product, that the physician was free to withdraw at that moment, and that she or he could keep the lunch. Even so, most interviewees who mistook me for a pharmaceutical

strains of HPV that Gardasil® covers, but has been shown to induce a greater antibody response to those strains (Einstein et al., 2009).

<sup>&</sup>lt;sup>9</sup> Medicentres Canada oversees a group of family medicine clinics that operate in four cities within Canada. They are walk-in clinics that offer extended hours with the stated goal of being accessible to patients (Medicentres, 2016). Despite this goal, I found that many Medicentres in the Edmonton and Calgary area appear to be constantly busy with long wait times for walk-in patients.

representative appeared to have only forgotten which day I was scheduled rather than that they had agreed to participate in a research project. Third, I wanted to include health professionals who were near the measles and pertussis outbreaks that occurred between 2013 and 2014. In addition, I was concerned about confidentiality if I remained in the Edmonton area. As such, I used departmental grant money to fund a research tour across central and southern Alberta.

I recruited participants over a short time period when driving south from Edmonton. I visited as many clinics possible in each town and city that I passed through. I stopped only to interview professionals who could accommodate me while I was visiting. I continued these efforts until I had sufficient narratives within the interviews to analyze, and had recruited enough participants from different localities to avoid confidentiality issues. In this process, I assumed that anyone who stated an interest in my project would have valuable stories and experiences to share with me. Therefore, I interviewed anyone who offered to participate, including a couple specialists (one nurse and one physician) who heard about my project through acquaintances. All other professionals with whom I spoke worked in family medicine, pediatrics, or public health clinics.

With my revised tactics, I conducted most interviews in physicians' offices and public health clinics over lunch breaks. A few interviews occurred in coffee shops and over the telephone. Interviews were semi-structured, because most participants would not speak freely without some guidance and prompts—a couple shared stories before I asked any questions (Appendix C). The purpose of my interview guide was to encourage conversation, gain background information, and ensure the coverage of certain topics, not to constrain the interview. When possible, I allowed health professionals to speak freely.

Unfortunately, my recruitment tactics and my need to concentrate interviews during trips through Alberta created time constraints. I could not analyze most interviews until after

collection. Some weeks I conducted up to five interviews and I averaged over two hours a day of driving in addition to several hours per day of recruitment efforts. Those weeks I found it impossible to keep up with transcription. Nonetheless, I reflected on my interview notes and research journal to inform potential topics for future interviews. I finished all but one interview in mid-summer 2014. I conducted the final interview in April 2015 with a physician who responded to my research invitation a year later.

#### The interviews

From the outset, it was apparent that interviewing physicians (more so than the nurses who partook in this project) upset traditional research power relationships:

One effect of having power reified into an authoritative discourse is that we talk as if

researchers *inherently* have more power in the research relationship. This problematic way of talking about the role of power stems from the dangerous and erroneous conflation of researcher power with researcher responsibility (Bloom, 1998: 35).

Unlike most research encounters, I was the subject with less authority and status during interviews with health professionals. I am not entirely certain how these dynamics impacted my interviews, but the interviews ran slightly differently from those I have done for previous projects. I found myself often waiting for busy clinicians and conducting short interviews when clinics were behind schedule, which occurred frequently. Some interviewees presented as though they were assisting me with completing my research. Others seemed to utilize me to promote their perspectives about a topic that they have found troublesome, given the recent disease outbreaks in Alberta. I was prepared to grant participants a great deal of control during the interviews, but most wanted more structure to the interview guide than I would offer. There were a few moments that I was uncomfortable. For instance, one physician seemed displeased that I did not bring the lunch that he had refused earlier and when he later flipped the interview to ask

me personal questions. Overall, such experiences were rare. I was pleased with how accommodating research participants were. Most participants seemed to value research and/or desired to help me complete my project. Furthermore, I held myself accountable to my research participants by offering them a synopsis of my findings upon completion.

Responses during the first few interviews demonstrated the importance of my research. For example, of my first four interviewees, one refused to be audiotaped because she said she was known to speak her mind. Another asked me to turn off the recorder for a short section of the interview with concern about controversy. Then, a third stated concerns about convincing patients that vaccines are safe in a medical world that is replete with pharmaceutical companies and financial conflicts of interest. Such commentaries kept me motivated during frustrating recruitment phases.

Most interviewees' appointments with patients ran into our interview time that was scheduled during the lunch, but once interviews began, they tended to welcome questions and grant me as much time as possible. Interview recordings ranged from under 13 minutes to over 55 minutes. That said, only two interviews were under 20 minutes and eighteen interviews were over 30 minutes. I incorrectly anticipated that many physicians would only be able to grant me fifteen to twenty minutes. I was pleased when interviews with talkative professionals ran far longer. The main reason that some interviews were short appeared to be the scheduling of unexpectedly complex patients before the interview.

While I hoped to interview some health professionals who would discuss their uncertainties with me, I targeted any professionals. I was concerned about how my project would read if I spoke exclusively with health professionals who expressed vaccine doubts. For instance, it is possible that such a project could be twisted into support of anti-vaccination proponents.

Furthermore, targeting skeptical professionals could bias the sample in such a way that would have limited my analysis of some of the main topics in this dissertation, such as professional accounts of self. Consequently, I resigned to analyze diverse perspectives. Many health professionals spoke as though they were certain about the necessity of vaccines. Nonetheless, even some of those who asserted that vaccines were safe, provided contradictory explanations about the financial interests of vaccine manufacturers, or vaccines that they considered unnecessary, ineffective, or less safe. I found interviews included data that lent easily to analysis.

After briefly asking interviewees about their professional backgrounds, I offered broad questions (i.e. 'What do you think is the biggest issue with vaccines in Alberta?' or 'How has your knowledge of vaccines changed since you began practicing?'). I included more structured questions as well to prompt interviewees if they failed to speak freely. When possible, I analyzed interviews on the same day that I checked transcripts for accuracy.

#### Ethics

Aside from resubmitting my ethics application to include a broader range of participants, I avoided unanticipated ethical concerns. Even so, it is important that I maintain participant confidentiality because a possibility exists that some participants provided information about which their family, colleagues, or professional organizations might disprove. As such, I removed identifiable information from transcriptions, stored paper copies of transcriptions in a secure filing cabinet, and encrypted electronic copies that I saved on my personal computer and USB drive. Prior to each interview, I reassured participants of their anonymity and/or confidentiality, acquired their consent on tape, and had them sign a consent form (Appendix B).

# The healthcare professionals

# The sample

All the healthcare professionals I interviewed worked in Alberta. The physicians had diverse backgrounds, whereas the nurses' backgrounds seemed similar to one another. Due to my own financial and time constraints, every participant in this project, practiced in or south of the Edmonton area. I travelled to southern Alberta because it had experienced a measles outbreak and was experiencing a pertussis outbreak when I was recruiting interviewees. With greater time and financial support, I also may have traveled to northern Alberta. Nonetheless, the sample of healthcare professionals who I interviewed is more than sufficiently large and diverse to meet the needs to this project.

To avoid using ethnically inappropriate pseudonyms, I refer to participants with names that are used in more than one culture. *Table 1* summarizes which names align with which professions.

Table 1. Participant pseudonyms (N=34)			
Family Doctors (N=20)		Pediatricians (N=6)	Public Health Nurses (N=4)
Adel	Johanna	Kellan	Tami (Nurse Practitioner, NP)
Damian	Kai	Mona	Tori (Registered Nurse, RN)
Aren	Zarah	Tobias	MaKenna (RN)
Kim	Ren	Javen	Amaya (RN)
Faris	Jayne	Chandra	
Milan	Anita	Taran	Family Medicine Nurses (N=2)
Kian	Maya		Olivia (RN)
Mariam	Nisa	Specialist (N=1)	Naomi (RN)
Jasmeen	Monica	Janna	
Rayaan	Aalia		Operating Room Nurse (N=1)
			Dena (Licensed Practical Nurse, LPN)

The physicians

Age: Thirteen physicians were between fifty and sixty years old, eight were between thirty-five and fifty years old, five were in their early thirties, and one was over seventy years old.

Physicians in their early thirties appeared to be new to the practice of medicine. Nonetheless,

some of them, along with the other physicians had international and/or interprovincial experience.

Cultural Background: I did not ask interviewees their immigration status or cultural heritage. Based on conversations with interviewees, it became clear than at least ten of the physicians had immigrated to Canada at some point in their lives. Around one-third of these physicians appeared to be non-white.

*Gender*: Twenty-three interviewees (sixteen physicians) presented as women and ten appeared to be men. Of the family physicians, twelve presented as women and seven as men. Of the pediatricians and specialists, three presented as women and four as men. As of 2013, the number of women in medicine was continuing to rise, with 43.1% of Canadian and 40.4% of Albertan family physicians now being female (CIHI, 2013).

Training: Only ten physicians I interviewed completed medical school in Alberta. Two physicians practiced part-time in Alberta and part-time in British Columbia. Nine of the remaining physicians completed medical school in British Columbia, Saskatchewan, Nova Scotia, Quebec, or Ontario. The remaining seven trained in various other countries, then immigrated to Canada. These countries included South Africa, Nigeria, Libya, Pakistan, and Ireland.

*Practice:* Of the twenty-seven physicians, five practiced (two part-time) in rural communities, four of these five maintained a family practice, and one practiced pediatrics. <sup>10</sup> One

<sup>&</sup>lt;sup>10</sup> Of these physicians, all practiced in towns with under 600 people per square kilometer and under 10,000 people total. I decided upon this definition to stay close to the Statistics Canada definition that rural communities have less than 400 people per square kilometer and a population of under 1,000 (Government of Canada, 2011). 10,000 people is far more than the 1,000 limit, but because of the low population density in the community that had the highest population and the interview participants' understandings of their communities, I have included it within the concept of "rural."

physician specialized in a field other than family medicine or paediatrics. Three physicians stated that they saw few children in their practice. The other physicians explained that the children they cared for was over thirty percent of their entire patient load. Two family physicians, who also worked in BC, explained that they worked primarily in a hospital. Other physicians explained that they had previous experience in anaesthesiology, sports medicine, obstetrics, emergency medicine, epidemiology, pharmacology, complementary and alternative medicine, women and child health, dermatology, developmental disabilities, and military medicine.

In addition, five physicians who participated had continued their education beyond medical school. Some of them had held academic positions and one said she had a PhD. Others explained that they attempted to enhance their vaccine knowledge by attending courses or conferences about vaccines or reviewing new vaccine information and updates that they received about public health in Alberta. Seventeen participants assisted in educating students and/or residents (some practices took on nursing students as well as medical).

Suffice to say, these physicians were diverse, which was reflected in their views regarding the efficacy, necessity, and safety of specific immunizations. The biases within this sample, however, likely reflected how busy a professional's practice was (in a couple cases clinic staff told me their physicians would not participate due to their patient load), levels of physicians' burnout (it is likely that burnt-out physicians opted-out of the study), the degree to which professionals were concerned with vaccines, and their openness to research. I cannot confirm with certainty the extent to which these biases affected my data and/or sample. Yet, I suspect that my interviewees had mixed motives for participating and that they told some of their stories for specific purposes. First, interviewees often provided a moral or take home message about vaccines or policy (e.g., some family physicians wanted permission to update tetanus vaccines

for adults without lacerations, some wanted to give the influenza vaccine to children under nine, and many described their frustration about vaccine refusals). Second, they seemed motivated to help with my project. Indeed, I perceived the data and stories that they offered to reflect what they believed I needed to complete my project. Third, some of them expressed support for academia and research, which may have motivated their participation. Healthcare professionals' testable or objective knowledge of vaccines is important to the care that they provide, but is beyond the scope of this project and my analysis tactics.

### The nurses

Of the nurses, all seven presented as women who appeared to be white. As of 2011, 93.4% of Registered Nurses (RNs) in Canada were women (CNA, 2013). One nurse was less than thirty years old, four nurses were in their mid-thirties, one was in her late forties, and one was in her late fifties. One nurse had trained in another province and one in another country. Four practiced in rural communities. The same number practiced in Public Health administering vaccines and providing health education. Two worked in family medicine clinics, one of whom also worked in a nearby hospital. One worked in the operating room at a hospital as a Licensed Practical Nurse (LPN). Another three nurses had prior experience working in a hospital.

Three of the four Public Health nurses were registered nurses and one was a nurse practitioner. In addition, one nurse was working towards a master's degree. Every nurse was strongly supportive and adamant about the necessity of all vaccines, although the LPN worked on a surgical unit and rarely treated children. That said, this sample of nurses was well educated about vaccines and included four Public Health nurses. Moreover, the remaining three nurses explained that they had completed some educational projects about vaccines: one for her own interests, another as a requirement to practice in Family Medicine, and one gained extensive

information from Public Health and similarly reputable sources to provide the best care possible to her children.

#### **Documents**

To complement my analysis of interviews, I analyzed public documents pertaining to the expectations and content of Alberta and Canada's vaccine programs. These documents are publicly available and offer instruction for health professionals who could also access profession-specific documents. These documents emphasized the value of vaccines. The Alberta document explained the importance of immunizations in population health. Likewise, the *Canadian Immunization Guide* attempted to allay apparently widespread uncertainties about vaccines by using "the best and most current publicly available scientific knowledge," then offered ample advice about communicating with patients, administering vaccines, and various other topics (PHAC, 2006a: 3, 22-54). Some health professionals referred to such government documents or shared statements that closely simulated those in these texts.

# Narrative analysis

Narratives can offer widely understandable explanations of dominant knowledge (including medical discourses), they can offer insight about contradictions to that knowledge, and they can mediate personal experiences through memory and language. During interviews, the interviewer and the interviewee create narratives collaboratively (Reissman, 2008: 23). Health professionals described their experiences, knowledge, and uncertainties regarding vaccines. These narratives took the form of *small stories*, which create meaning, but involve sharing an event rather than a life story (Squire, Andrews, and Tamboukou, 2008: 7). Some of the descriptions deviated from most definitions of "narrative," but are comparable to dominant cultural (grand) narratives and medical discourses about vaccines. Many interviewees shared some contradictory information or

"counter-narratives," which deviated from grand narratives about vaccines (see Heller, 2008). Stock images emerged within the interviews as both supportive statements of vaccines and contradictions to them. Stock images are the common occurrences that appear within narrations that emerge from a particular social position (Maynes et al., 2008: 81)—in this case, the social position of a health professional. The presence of these stock images enable a researcher to understand how narrators from similar social conditions represent their experiences and provide information about the social, political, and economic ethos (Andrews 2002: 11; Maynes et al., 2008: 136).

I use stock images from interviews in each chapter to explain various topics. <sup>11</sup> Specifically, some ways interviewees expressed their certainty in the vaccine narrative, their uncertainty about specific vaccines issues, their professional role and learning, their experience educating patients through stories, and their responses to public counter-narratives about vaccines. Common stock images offered support to the dominant cultural narrative that presents vaccines as safe and life-saving treatments, which had rid disease from the population (see Heller, 2008). Counternarratives most often involved expressions of uncertainties or stories about the inefficacies of specific vaccines. Health professionals offered various perspectives about their role in patient education, the influence of narrative during patient encounters, and their own learning about vaccines.

Narrative analysis allows insights about relationships with others because it targets stories that usually involve information about one's interpersonal relationships. Through narrative analysis, one can investigate social relationships (Andrews et al., 2004: 1). These portrayals of

<sup>&</sup>lt;sup>11</sup> To identify these stock images, I labeled themes in each interview, related them to the dominant narratives in each interview, and compared them across interviews. In addition, I compared these narratives to the grand narrative about immunization, narratives in government documents, and some of the widespread concerns about immunization.

various characters help healthcare professionals explain their relationship with patients in relation to vaccines. Narrative analysis can be particularly useful for investigating issues of subjectivity and social action (Maynes, Pierce, and Laslett, 2008: 16). Indeed, narrative can offer reflections about the presentation of self and about one's group in relation to dominant norms and others (Riessman, 2008: 7; see Butler, 2005). As such, the narratives and stock images I analyzed conveyed information about healthcare professionals, their knowledge, and their practices.

In his book about the vaccine narrative, Jacob Heller (2008) explained that all narratives include "a specific sequence of events with particular consequences" (Heller, 2008: 9). In addressing each of these topics, I delved into the perceived consequences associated with the course of events, but also to the interviewees' understandings that justified the particular story as representative of their experiences. I paid attention to healthcare professionals' characterization of themselves, other healthcare professionals, anti-vaccine proponents, patients who refuse vaccines, and compliant patients.

# **Chapter Three**

# From Coxpox Pus to *Vaccine Roulette*: Narratives about Vaccination Successes and Risks Introduction

When Edward Jenner first injected cowpox pus into a young boy, the medical community could not explain the boy's subsequent resistance to smallpox (Heller, 2008: 35; Ogbogu, 2014: 37). Prior to germ theory in 1861 and explanations of immunity, there could be little to no medical understanding of the success of vaccination, its predecessor inoculation, or why people seemed to only contract certain diseases once in a lifetime (Chen, 2005: 41; Ogbogu, 2014: 27; Wootton, 2006: 6). Vaccines initially gained popularity primarily through anecdotal reports of smallpox prevention. I review some of the narratives about the safety, risk, and uncertainty that have surrounded immunization throughout history. As much as possible, I include medical professions' and dissident professionals' narratives about immunization from the emergence of the first inoculations to the twenty-first century vaccines.

Most social science inquiries into contemporary vaccine anxieties revolve around anti-vaccination advocacy and discourses, uncertainties, and risks. Recent controversies in many countries have forced physicians to acknowledge how anti-vaccination discourses influence their practice (Blume and Zanders, 2006: 1826). Health professionals likely respond to parental concerns regarding particular issues, such as whether the MMR vaccine could cause autism

<sup>&</sup>lt;sup>12</sup> In recent years, the terms inoculation, immunization, and vaccination have been used interchangeably (Kitta, 2012: 8). Each term, however, is slightly different. Immunization, "refers to the introduction of a vaccine in order to elicit an immunological response" (Kitta, 2012: 8). Inoculation involves exposing a person to material from a weakened disease through a skin wound or mucous membrane (Gronim, 2006: 248; Kitta, 2012: 8; Marcovitch, 2006: 354). Vaccination means improving immunity to a particular disease, which involves exposure to a killed microorganism, weakened microorganism, or a substance that resembles the disease. That is, the components of a vaccine can be active or passive, and natural or artificial (Kitta, 2012: 8).

because most anti-vaccination discourse disputes specific vaccines or specific children (Hobson-West, 2007: 204; Poltorak, Leach, Fairhead, and Cassell, 2005: 717).

Despite concerns about vaccine safety, however, the culturally dominant narrative about vaccines is that vaccines save lives (Heller, 2008). This narrative emphasizes that vaccines are safe and effective. Jacob Heller (2008) wrote about how vaccines are a cultural phenomenon that are continually accepted and supported because of narratives that demonstrate their efficacy in preventing death and maintaining health. He argued that the success of vaccination relies upon narratives because scientific explanations of epidemiology, immunity, and probabilities require a kind of scientific literacy that renders them inaccessible to the general public (Heller, 2008: 11). This narrative contains the moral that vaccines are the best and only way to fight disease, and it leaves any contradictions unmentioned (Heller, 2008: 13).

Smallpox was the first major success of vaccination, but compelling narratives about containing polio, pertussis, measles, and various other diseases soon followed. Despite these successes, the dominant narratives about vaccines overlook early controversies involving mandatory smallpox vaccination or the risks associated with early polio vaccinations. As such, smaller counter-narratives emerged that emphasize perceived risks and uncertainties, such as erroneous statements that the pertussis vaccine causes disability or that the measles vaccine is linked autism. In recent decades, narratives and popular demand remain influential on the public acceptance of various vaccines. Likewise, public concerns and fears have contested some vaccines until the government allowed for the policy changes that would subdue public concern and improve vaccine uptake (see Blume and Zanders, 2006). Such changes include the removal of thimerosal from vaccines or the inclusion of some basis for conscientious exemption from mandatory vaccination (PHAC, 2007: 3).

In this chapter, I trace narratives about risk, uncertainty, and safety from smallpox inoculations to contemporary understandings of vaccines. First, I provide a background for medical history and theories about medical knowledge. Second, I detail the concepts of inoculation, immunization, and vaccination and discuss their origins. Third, I review professional ambivalence to the smallpox vaccine. Fourth, I discuss how vaccines established their reputation as medicine's greatest lifesaver because of the eradication of smallpox and containment of poliomyelitis. Finally, I review some controversies involving polio, pertussis, and the measles vaccine in relation to contemporary narratives of vaccine risks and uncertainties.

# Medical progress, inoculation, and normalization

Although effective, the smallpox inoculation and later the vaccine appeared at a time when many medical treatments did more harm than good and when smallpox was one of the leading causes of death (Marble, 1993: 6). Many less safe and less effective medical treatments remained in practice long after the discovery of safer alternatives because of various factors, including professional pride: "For 2,400 years patients believed that doctors were doing them good; for 2,300 years they were wrong" (Wootton, 2006: 2). Indeed, treatments that the medical community widely accepted until the turn of the nineteenth century utilized "heroic cures," which involved drastic experimental interventions, such as extensive blood-letting, purging, or treating with toxins such as mercury that harmed patients (Hohertz Baracco, 2008: 15). David Wootton (2006) argued that most medical practice, including some in present day, "has not been evidence-based" and was ineffective (p. 3). In the nineteenth century, both the medical and alternative professions, such as homeopathy, were equally poor at curing malaise. Although homeopathy was less fearsome to patients, medicine eventually gained more cultural legitimacy and underwent radical changes to become more effective (Abbott, 1988: 54).

Many historical accounts of medical science present changes in knowledge as if they were linear progression that involved little change (Wootton, 2006: 3). Judith Butler (2005) suggested that scientific thought is presented as though its history has been a series of accurate truth claims: "For science to admit a history was a scandalous claim for those who claimed that science, in its rationality, had a truth that is transhistorical" (Butler, 2005: 117). Butler (2005) used the word "transhistorical" to argue that scientific knowledge is presented as though each discovery presents an accurate account of reality that will remain factual as future scientific knowledge is built around it. Despite widespread beliefs, the idea that knowledge progresses linearly is a myth (Eriksen, 2013: 517).

The discovery of germ theory was major shift in medical knowledge, which transformed, rather than progressed, the treatment of disease. This discovery occurred after smallpox vaccines and inoculations came into widespread use. Unlike many other treatments, inoculation was effective at preventing the spread of wild smallpox. The appearance of inoculation efficacy spread through public demand and narrative, rather than medical knowledge (Heller, 2008: 35). Popular support of inoculation began prior to governmental mandates, sometimes with opposition from government officials. The smallpox inoculation and later the vaccine found wide acceptance based on personal testimonial and stories, rather than scientific evidence and clinical trials (Gronim, 2006: 250; Heller, 2008: 34; Kitta, 2012: 9; Reidel, 2005: 24; Wootton 2006: 6, 14). That is, medicine's greatest success story, the vaccine narrative, began through narrative support and without medical consensus.

Centuries before medical explanations of immunity, popular conceptions of immunity influenced health behaviours (Wootton, 2006: 14). 13 By 430 BCE, survivors of smallpox would

<sup>&</sup>lt;sup>13</sup> Immunity could result from inoculation or from exposure to wild smallpox within a

nurse new smallpox victims because they would not become ill again (Riedel, 2005: 22).

Moreover, people would intentionally expose children to diseases that were more dangerous to adults through "pox parties," which became common practice by the 1700s (Kitta, 2012: 8). 
Smallpox was omitted from "pox parties" because it was more deadly than so-called "childhood" diseases (such as measles, mumps, rubella, and chickenpox). Rather, the most successful way to combat smallpox-related deaths prior to vaccination was inoculation.

Inoculation is most often used in reference to conveying immunity to smallpox. It involved bringing infected material of a disease into a body through a small wound in the skin or mucous membrane (Gronim, 2006: 248; Kitta, 2012: 8; Marcovitch, 2006: 354). For instance, inoculation against smallpox could be done through a mucous membrane by intentionally placing matter from a dried and ground smallpox pustule material in a person's nose (Boylston, 2012: 312; Kitta, 2012: 8). Inoculation constituted the first attempts to immunize bodies against smallpox, an infamously deadly disease. Various forms of inoculation against smallpox were used throughout Southeast Asia and the Middle East for centuries before the practice spread to Europe. Even so, little written history about immunization existed prior to the seventeenth

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community (Marcovitch, 2006: 354). "Acquired immunity depends upon the immune system recognizing a substance as foreign the first time it is encountered, storing this information so that it can mount a reaction the next time the substance enters the body. This is the usual outcome of natural infection or prophylactic IMMUNISATION" (Marcovitch, 2005: 354). This process involves the memory of the initiating antigen. Priming the immune system for this response is the physiological basis for vaccination programs (Marcovitch, 2005: 354).

<sup>&</sup>lt;sup>14</sup> "Pox parties" are still used by some parents, but they were more heavily relied upon prior to vaccination, with the intention of exposing children to such diseases as the chicken pox, which are likely less threatening to younger children. For instance, pox parties lost some appeal following the advent of the varicella vaccine (chicken pox [Kitta, 2012]).

<sup>&</sup>lt;sup>15</sup> Variolation, which is often used interchangeably with inoculation, is another word for inoculating against smallpox (Marcovitch, 2005: 755; Reidel, 2005: 22). Variola is a word for smallpox, which includes three strains: *variola major* is the deadliest variant and known as smallpox, *variola minor* is milder, and *variola vaccinae* is known as cowpox (Marble, 1993: 6). Variolation means inoculation with variola (Bliss, 1990: 45).

century (Kitta, 2012: 8). Inoculation was most often understood as a means to control an unavoidable illness or experience a less severe version of smallpox—although, this less severe version accompanied the possibility of contracting or spreading the disease in its full severity (Eriksen, 2013: 522). Health professionals and the public expressed doubts regarding attempts to control the spread of smallpox through the use of antigens.

Early smallpox inoculations demonstrated results that were medically inconceivable. Even so, Michel Foucault (2004) argued that these practices gained widespread support because of the statistical measurements of results and what some English translations of his work call apparatuses of security (pp. 58-60). Apparatuses of security are a form of power that Michel Foucault (2004) claimed emerged counter to power that he argued operates through discipline. Discipline is a mechanism of power that regulates individuals within the social body, whereas apparatuses of security focus on the population (Foucault, 2007: 57). Foucault (1980a) clarified that power produces knowledge (p. 55). Unlike apparatuses of security—which calculate the average or mean and attempt to normalize a population towards that average—discipline classifies behaviours and bodies as the ideal and attempts to motivate individuals to pursue those ways of being (Foucault, 2007: 57). That is, discipline relies on hidden mechanisms—including architecture, the production of knowledge, body posture, individual health, and so forth—to promote a form of being that best approximates a set of objectives (Foucault, 1980a: 59; 1980b:

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<sup>&</sup>lt;sup>16</sup> Foucault (1980b) used the French term *dispositif* to refer to what some translators have called apparatus, mechanism, or deployment. He explained that dispositif (or apparatus) was a "heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative procedures, scientific statements, philosophical, moral and philanthropic propositions—in short, the said as much as the unsaid. [...] The apparatus itself is the system of relations that can be established between these elements" (Foucault, 1980b: 194). He specified that apparatuses emerge at a time of "urgent need" (in this case, need to combat disease and death [Foucault, 1980b: 195]). As such, theoretical discussions of apparatuses or dispositifs extend beyond the description I provide.

105). Through these hidden mechanisms, discipline addresses one specific problem, whereas security plans for uncertainty and a variety of possible events. For example, security acknowledges that some bodies may be at greater risk to disease than others, and that some time periods may experience epidemics (Foucault, 2007: 20). Alternatively, discipline focuses on ensuring that individuals undertake specific behaviours, such as receiving a vaccine.

The apparatuses of security incompletely replaced discipline, which proved essential to managing the population (Foucault, 2004: 107). Foucault used the smallpox inoculation and vaccination to exemplify how the apparatuses of security operate through public health (p. 60-62). His claims may reflect how inoculation gained state support (although, large segments of the population used inoculation prior to any medical or state encouragement [Eriksen, 2013; Gronim, 2006: 253; Reidel, 2005: 22]).

Foucault's (2004) apparatuses of security offer a useful account of how smallpox-susceptible populations in some countries became *normal* in the nineteenth century.<sup>17</sup> To regulate subjects, the apparatuses of security rely on *normalization* and discipline relies on *normation*. Both concepts are relevant to the narratives that support vaccination. Discipline begins with a norm

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<sup>&</sup>lt;sup>17</sup> Foucault went on to discuss *governmentality* and *biopolitics* throughout his works. According to Foucault (2004), governmentality emerged with the introduction of the state and specifically with the inclusion of economy in politics (p. 95). Governmentality aimed to manage individuals, goods, and wealth through the family and particularly through the father (Foucault, 2004: 95). Governmentality operates through a collection of various "institutions, procedures, analyses and reflections, calculations, and tactics," which allow for the exercise of power over the population (Foucault, 2004: 108). With governmentality, apparatuses of security form a "technical instrument," which is used to help guide the population towards the goals of the political economy (Foucault, 2004: 108). He emphasized that governmentality is a process, rather than a result, which has gained superiority over all other forms of power (Foucault, 2004: 108). Foucault expanded this definition to include any factors that govern both individuals and the population. In relation to health, Foucault (2004) emphasized that *biopolitics* emerged in relation to mid-late eighteen century European developments in "public hygiene" and "social medicine" (p. 367). Biopolitics treat the population as a group of living bodies with "particular biological and pathological features" (Foucault, 2004: 367).

(e.g., the ideal healthy body), whereas security plots the normal and abnormal to calculate the statistical likelihood of disease for different categories of the population (Foucault, 2004: 57, 61). As such, discipline involves *normation*, which creates the norm, and thereby, the normal and abnormal (Foucault, 2004: 57). Alternatively, the apparatuses of security, derive *normal* from supervision and statistical measurement of the favourable commonalities within the population (Foucault, 2004: 57). This is *normalization* in the strictest sense because it reflects what is normal within the existing population (Foucault, 2004: 63). Indeed, people are to behave in obedience to the population rather than to a sovereign ruler: "Man is to population what the subject of right was to the sovereign" (Foucault, 2007: 79). Consequently, people are to exercise obedience by remaining within a specified range of acceptable behaviours.

Concerning vaccines, a normal body—based on either definition—is an immunized body; vaccinated being a proxy for immune. Immunized bodies constituted those who are deemed the least likely to transmit diseases to the population. The apparatus of security operates to protect segments of the population that are statistically proven to be most vulnerable, and whose lives are valued (e.g., infants and young children). Immunization particularly helps protect those in the population who have the greatest statistical likelihood of experiencing disease or complications relating to disease (see Foucault, 2007: 61). In order to be considered compliant with public health, one must be immunized either by surviving a vaccine-preventable disease, or receiving a vaccine for that disease.

Normation and normalization both relate to the vaccine narrative. This grand narrative paints those who do not comply as the "bad guys" (see Heller, 2008: 22) similar to how disciplinary measures labels them for deviating from ideal behaviours that comprise norm. Completely vaccinated bodies are the "good" because they ensure population immunity and safety; this is

especially true for children. Yet, normalization also operates when vaccines gain legitimacy through discussions of herd immunity, which secures the health (and therefore normality) of the population. Indeed, statistical measures suggest that most people are vaccinated and that those vaccinated are at the least risk to spread disease. That is, to be normal is to be vaccinated. Through this construction of normal, apparatuses of security work by averting statistical risks of disease and death. As such, public health campaigns exercise power by promising life to those who adhere to their treatment regimens rather than threatening death to those who resist (Kaler, 2009: 1717; see also Fries, 2008: 355). These campaigns began by promoting inoculation, the smallpox vaccination, and eventually, vaccination against a long list of now preventable diseases. Foucault (2004) offered substantial insights into understanding how power operates in generating population compliance with vaccination. In what follows, I discuss historical moments, knowledge, and narratives about vaccination and inoculation rather than extending upon the above Foucauldian analysis.

# *Inoculation and uncertainty*

Some historians claim that intentional inoculation attempts began over two thousand years ago in India and/or China (Boylston, 2012: 312; Kitta, 2012: 8; Mnookin, 2011: 24). Inoculation was popular throughout parts of the Balkans, Africa, and Asia long before it reached Western Europe (Boylston, 2012: 310-311; Kitta, 2012: 9). Reports of attempts prior to the mid-sixteenth century are only speculative, but evidence of early inoculations has been found in India and China (Boylston, 2012: 311). By the early 1700s, the practice of inoculation had spread throughout various parts of the world, including the Ottoman Empire and Europe where written

records of the practice became common (Boylston, 2012: 310-311; Reidel, 2005: 22; Hardon, 2004: 262).<sup>18</sup>

Historical accounts of eighteenth century inoculation often draw on assumptions that inoculation was widely understood and credited aversion to inoculation "to the absence of decisive leadership, to religious commitments, to professional jealousy, or to simple lack of access" (Gronim, 2006: 248). Nonetheless, early inoculations were rife with uncertainty and doubt: "to give oneself the disease deliberately was to approach an abyss of death or disfigurement: there was no obvious reason (nor is there still) why smallpox contracted through inoculation would somehow be different from smallpox contracted inadvertently" (Gronim, 2006: 249). Inoculation was a controversial novelty when introduced to Europe, yet many physicians viewed it as complementary to eighteenth century medical knowledge and traditional humoral pathology (Eriksen, 2013: 518, 521, 524). Because of their focus on humoral pathology, physicians who practiced early inoculation took immense care to prepare each patient for the procedure (Eriksen, 2013: 518, 524).

It appears that narratives from physicians were influential in acceptance and demand for the treatment since the earliest inoculations. For example, inoculation became common practice in

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<sup>&</sup>lt;sup>18</sup> In Europe, English aristocrat Lady Mary Wortley Montague is credited with bringing knowledge of inoculation from Istanbul and pressuring physicians to take up the practice (Marble, 1993: 8; Reidel, 2005: 22). In response to Wortley's efforts, embassy surgeon Charles Maitland (who had previously inoculated Wortley's children) conducted successful medical experiments with the support of the British government on six prisoners at Newgate and orphaned children in 1721 (Bliss, 1991: 44; Reidel, 2005: 22). Maitland then successfully treated the Prince of Wales's two daughters, and the practice gained widespread acceptance (Marble, 1993: 8; Reidel, 2005: 22).

<sup>&</sup>lt;sup>19</sup> Of course, ethics and religious belief had some influence on inoculation. For example, in 1722, Reverend Edmund Massey condemned inoculation because he argued that disease was to be inflicted by God and not by humans (Eriksen, 2013: 520). Other religious leaders, however, constructed religiously-based pro-inoculation arguments by claiming that inoculation was a gift from God (Eriksen, 2013: 520).

eighteenth century England, where physicians often advocated for the practice. Conversely, inoculation was less common in France, where few physicians promoted inoculation (Eriksen, 2013: 518). Pro-inoculation discourses spurred from various sources (including religious advocates who believed God wanted population growth). Some pro-inoculation arguments resonated with contemporary pro-vaccine discourses: "Inoculation was also defended as a parental responsibility. Not to inoculate one's children was to neglect the duty to protect them" (Eriksen, 2013: 520). Inoculation knowledge and physical vaccination components circulated across borders even before knowledge of the need to control disease on a global scale emerged. Despite differences in preferred forms of inoculation between countries, "Influential texts circulated widely and crossed national borders" (Eriksen, 2013: 519).

Immense risks, however, accompanied inoculation. Inoculation often caused mild smallpox, recipients could also develop disseminated smallpox and spread smallpox even without displaying symptoms themselves, or they could receive other blood borne illnesses from the procedure such as syphilis or tuberculosis (Gronim, 2006: 248; Reidel, 2005: 22). Even so, in Europe, the probability of these side effects in the eighteenth century was two to three percent, which was ten times lower than the risks of harm associated with the disease (Reidel, 2002: 22). Some practitioners attempted to reduce risks from inoculation by weakening the biological material from smallpox sores through time or exposure to heat and herbs (Boylston, 2012: 312). These risks, decreased as inoculation tactics advanced, but critics of inoculation compared population risks when there was an absence of smallpox in the population, rather than risks during an epidemic (Eriksen, 2013: 524).

Smallpox, and eventually inoculation, followed the colonists to North America with catastrophic effects—some intentional—for the indigenous people who they displaced on that

continent. Inoculation spread to North America in part through African slaves who shared their knowledge with a slave owner, Boston minister, and Harvard College graduate, Cotton Mather (1663-1728). Wide segments of many small settlements (such as New York) adopted inoculation (Gronim, 2006: 251).<sup>20</sup> Indeed, the 1730s appeared "to be the perfect situation encouraging the embrace of inoculation: an urgent threat, a set of clear directions, and the concrete local experience of its efficacy" (Gronim, 2006: 253). In 1721 in Boston, Reverend Cotton Mather and Dr. Zabdiel Boylston's (1676-1766) support of inoculation proved integral to uptake at that time, but they faced immense opposition from much of Boston's medical community (Marble, 1993: 8; Gronim, 2006: 248; Kitta, 2012: 9; Reidel, 2005: 22).<sup>21</sup> The population supported Mather and Zabdiel's inoculation because they preferred to risk the 2-4% mortality rate of the inoculation to the 14-30% mortality rate with the disease, which was 15-45% higher for women and small children (Kitta, 2012: 9; Ogbogu, 2014: 25; Reidel, 2005: 22).<sup>22</sup>

Many physicians had varied opinions about inoculation and its various application methods. For example, in South Carolina, Dr. James Kilpatrick (1690-1770) recommended preparation for inoculation through "several weeks of purging, bleeding, and limited diet, all intended to rid the body of excessive or corrupted humors" (Gronim, 2006: 257). Similarly, a 1775 newspaper notice suggested that poor families in Nova Scotia inoculate themselves following "a lengthy period of abstinence from meats, spices, wine, and all seasoned food prior to the inoculation, a

<sup>&</sup>lt;sup>20</sup> Although inoculations spread widely, the practice did not spread as readily among Native Americans in and around the New York area (Gronim, 2006: 260).

<sup>&</sup>lt;sup>21</sup> Over time, Mather and Boylston's work proved medically influential, perhaps partly because the United States army experienced the devastating effects of smallpox when fighting inoculated British troops for control of Quebec (Reidel, 2005: 22).

<sup>&</sup>lt;sup>22</sup> Stefan Reidel (2005) gives lower death estimates for both the inoculation and disease, but he bases his numbers on the statistical reports Mather and Zabdiel's made to support their initiatives (22). These different rates most likely result from variation between outbreaks (Gronim, 2006: 248).

'Vomit of Tarr' three days before, and calomel in a pill on the day of the inoculation' (Marble, 1993: 103). Nonetheless, some policies responded to measureable risks associated with inoculation. For instance, a 1775 act in Nova Scotia directed those being inoculated to ensure that their home was a minimal distance from other residents and Dr. George Greaves advised that he was running an inoculation house in the suburbs of Halifax (Marble, 1993: 104).

# *Cowpox pus and the eradication of smallpox*

Many medical historians credit England's Edward Jenner (1749-1823) with creating the first vaccine (Kitta, 2012: 9). In 1796, Edward Jenner created what historians recognized as the first successful and scientifically unproven vaccination against smallpox (Reidel, 2005: 23; Strassburg, 2007: 260). Popular use of vaccines following Jenner's smallpox experiments demonstrated that socially supported vaccination could spread without scientific and medical support: "with insufficient immunological knowledge, mass vaccination can only be accomplished through social consensus or other special situations" (Chen, 2005: 41). Almost 70 years after Jenner's vaccine came into use, France's Louis Pasteur (1822-1895) proposed the germ theory of disease. Pasteur added some scientific explanation for vaccination when he hypothesized that diseases were caused by microorganisms, and in 1885, he invented the rabies vaccine to treat people exposed to that disease.

Jenner's discovery began with his suspicion that milkmaids had immunity to smallpox from their exposure to cowpox. He injected an eight-year-old boy, James Phipps, with matter from the lesions on Sarah Nelms's hands (a milkmaid who was suffering from cowpox [Rediel, 2005: 23]). After waiting ten days for Phipps's symptoms to subside—lost appetite, mild fever, discomfort in the axillae—Jenner injected the boy again with smallpox matter and waited for him to become ill, but no disease developed (Reidel, 2005: 23). As with so many medical discoveries,

Jenner did not discover vaccination, so much as "confer it scientific status" and "pursue its scientific investigation" (Reidel, 2005: 25).<sup>23</sup> Jenner became a central figure in the vaccine narrative and he was integral to normalizing vaccination because of his ability to brand, name, and sell his vaccine.

Jenner's claims faced harsh criticism and his initial efforts to publish his findings were rejected (Reidel, 2005: 24). The theories that backed Jenner's experiment deviated from the established medical knowledge and research tactics of the time. His theories faced harsh criticism because medicine works to refute findings that deviate from its professional knowledge (Abbott, 1988). Jenner produced evidence that vaccination created resistance to smallpox, but without scientific understanding (Reidel, 2005: 24), many professionals doubted the efficacy and safety of his vaccine. As such, he initially published his findings privately in 1798, coining the term *vaccination* from *vacca*, which is latin for cow and *vaccinia*, which is cowpox. As such, vaccination meant "inoculation with the material of cowpox," which is used to prevent future infections with smallpox (Marcovitch, 2005: 752; Reidel, 2005: 24).

Furthermore, although vaccination against smallpox involved less risk than inoculation and spontaneous smallpox epidemics, his opposition cited various risks and ethics. Some of his opposition cited the all-too-real risk of various adverse reactions and exposure to blood borne diseases (Bliss, 1990: 48; Leach and Fairhead, 2007: 60). In fact, even the last renditions of the smallpox vaccine created more side effects than any other vaccines that existed in the early 2000s, which included "the severest manifestations of generalized vaccinia, encephalitis, eczema"

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<sup>&</sup>lt;sup>23</sup> Despite historical credit, however, it is highly unlikely that Jenner was the first person to attempt vaccination (Bliss, 1990: 46). In 1774, a man named Benjamin Jesty (1737-1816) was likely first to vaccinate his family. Jesty used material from the udders of cattle on his wife and two sons. In fact, eighteenth century English country physicians' use of inoculation with smallpox and cowpox to prevent smallpox was fairly common in counties with a strong dairy industry (Reidel, 2005: 25).

vaccinatum, progressive vaccinia, and fetal vaccinia" (Haselow, 2016: 130). Unlike inoculation, however, vaccination could not result in an unintentional spread of smallpox (Marble, 1993: 8).

Within four years of its creation, "[d]espite errors, many controversies, and chicanery," vaccination had spread throughout most of Europe (Reidel, 2005: 24). Millions of people worldwide had been vaccinated within twenty years of Jenner's discovery (Bliss, 1990: 47). Between 1818 and 1820, Jenner's new vaccine had halved smallpox deaths, but faced immense resistance in Britain by the 1850s (Offit, 2011: 108). The quick reduction in smallpox related deaths reflected how quickly the practice of vaccination spread throughout the world. Vaccination came to what is now Canada in 1798 when Reverend John Clinch (1749-1819) requested a supply of the vaccine (Ogbogu, 2014: 37). After 1798, inoculation became increasingly recognized as higher risk than vaccination. As such, restriction of inoculation and adoption of vaccination spread slowly. As provinces joined the confederation, they adopted similar vaccine policies to the two provinces that legal scholar Ubaka Ogbogu (2014) wrote about in his dissertation (p. 17). Nova Scotia was first to adopt vaccination in 1850 and restrict inoculation to certain months of the year in 1799 (Marble, 1993: 158; Ogbogu, 2014: 38). Similarly, in 1853, the Province of Canada (now Ontario) passed legislation that made persons practicing inoculation liable to face up to a month in prison and a permanently revoked medical license (Ogbogu, 2014: 80). Alberta introduced routine immunization against smallpox in 1916 and began recording cases in 1919 (Government of Alberta, 2015: 15).

Vaccine supplies, however, were limited and costly in the 19<sup>th</sup> and 20<sup>th</sup> centuries (Ogbogu, 2014: 36). Furthermore, some Canadian medical professionals from the mid-1800s critiqued vaccination with editorial statements that vaccination was "by no means preventative" of smallpox (qtd. in Ogbogu, 2014: 84). At the time, medical research about smallpox treatment

tended to investigate treatments that eventually proved ineffective (i.e., "puncturing diseased pocks and applying poultices, leeching and 'tincture of iodine'" [Ogbogu, 2014: 85] see also Marble, 1993: 7). Even so, some physicians began using vaccination as a means to promote their individual professionalism and specialized expertise (Ogbogu, 2014: 104-105).

Anti-vaccination organizations emerged immediately in various districts to counter the adoption of vaccination. By 1879, following the implementation of compulsory smallpox vaccination in the United States, several anti-vaccination organizations emerged (Blume, 2005: 628). "Irregular physicians" often led early vaccine resistance in the USA, which targeted the public health legislation that mandated vaccination (Blume, 2005: 628). As states integrated rights to opt-out of vaccines into public health policies and vaccination gained scientific support, anti-vaccination organizations and resistance receded (Blume, 2005: 628). Vaccine resistant groups emerged in Canada as well and critiqued vaccination on various grounds (Ogbogu, 2014: 31).

Unlike recent anti-vaccination advocates, who are predominantly middle and upper class, nineteenth century opposition to vaccination often arose from the poor and working classes, who frequently experienced the stigmatizing enforcement of public health laws (see Blume, 2005: 628; Kitta, 2012: 12). For example, in mid-1800s England and Wales, only the wealthy could afford to receive compulsory vaccinations from medical practitioners, whereas others were vaccinated by Poor Law Guardians, and non-compliers were under the surveillance of civil servants (Blume, 2005: 629). Similarly, following major outbreaks in New York (1901-1902) and Boston (1893-1894), smallpox vaccine promotion often targeted new immigrants and lower income communities (Kitta, 2012: 19). As such, vaccination was increasingly associated with

classism and racism (Kitta, 2012: 19). Many "irregular physicians" accompanied or led popular protests against mandatory smallpox vaccination (Blume, 2005; Kitta, 2012: 19).

Smallpox eradication became one of medicine's greatest success stories. Even so, eradication occurred slowly because of misconceptions, such as the failure to recognize that multiple vaccinations were required to develop lifelong immunity to smallpox (Bliss, 1990: 49). Moreover, several innovations that emerged in the mid-1900s increased the efficacy of vaccination (Strassburg, 2007: 260). Physicians at the time lacked many of the technologies that help make vaccination safe and effective. First, they lacked the heat stable, freeze-dried vaccines that came about in the 1950s, which meant that vaccines were extremely difficult to administer in regions with less access to electricity and refrigeration. Second, they lacked bifurcated needles, which ease the use of vaccines and increase immunity when compared to the multiple puncture technique that Jenner used. And third, despite support from the World Health Organization, many countries (especially countries with insufficient resources) were incapable of instituting a successful mass vaccination campaign until after smallpox was eradicated. Constraints on program implementation were due to various reasons in different countries (such as cost, administration, skepticism that diseases can be eradicated) and availability of healthcare workers (Strassburg, 2007: 260-265). In 1967, smallpox was epidemic in over thirty countries, with ten million cases estimated worldwide (Strassburg, 2007: 260). In fact, "surveillance and containment" became key features in many countries efforts to finally eradicate the disease when mass vaccination was not possible (Strassburg, 2007: 260).

Nonetheless, the last case of smallpox in Alberta occurred in 1943 and smallpox was declared eradicated from Canada in 1946 and from the globe in the late 1970s (Government of Alberta, 2015: 15; Ogbogu, 2014: 26; Reidel, 2005: 25; Straussburg, 2007: 259). Wealthy

countries stopped vaccinating against smallpox in the 1960s and Canada discontinued use of the smallpox vaccine in 1980 (Government of Alberta, 2015: 15; Bliss, 1990: 269). The smallpox vaccine saved many lives in the nearly two hundred years it took to remove the threat of that disease (Strassburg, 2007: 260). As smallpox was disappearing from the globe, other vaccines were being developed for use in industrialized nations (Hardon, 2004: 263).

# Medicine's greatest life saver

Cultural narratives about the efficacy of vaccines overwhelmingly describe successes at containing disease (Heller, 2008: 11). Through vaccines, many believe, "our science demonstrates human mastery of death" (Heller, 2008: 22). Heller (2008) argued that the culturally dominant vaccine narrative depicts vaccination in a simplistic and positive light. He argued that this narrative sanitizes many of controversies and errors that accompanied the creation of herd immunity and containment of disease. Nevertheless, both controversies and widely publicized embellishments of vaccine-related risks have contributed to ongoing suspicions of vaccination. Contemporary divisions in expert opinions of vaccines are much less intense than they were in the 1800s, but they include occasional support of imaginary vaccine risks (Heller, 2008: 35-36).

In the twentieth century, popular anti-vaccination discourses gained large-scale media attention (Leach and Fairhead, 2007: 83; Wolfe and Sharp, 2002: 431). Media coverage has the ability to create the appearance of truth in absence or contradiction to unpublicized scientific information (Beck, 1992: 169). With vaccination, this attention creates the appearance that substantial divisions in expert opinions exist, that extensive gaps in knowledge exist, and more generally, that vaccination involves great risk. Although they are increasingly rare, tragic vaccine mishaps have harmed and killed children. For example, the polio vaccine is another of

medicine's greatest success stories, but this vaccine caused public and medical concern in the mid-1900s. Likewise, smaller, but similarly concerning incidents have involved various vaccines, such as the BCG (tuberculosis) vaccination in 1921, the yellow fever vaccination in the early 1940s, the diphtheria vaccine in the 1940s, and the swine flu vaccine in the 1970s (see Heller, 2008: 19-20, 47-48; Offit, 2011: 55-56). Below, I review controversies involving the polio, pertussis, and measles vaccines, which raised notable safety concerns among the public and some professionals.

## Poliomyelitis and clinical trials

In 1952, Jonas Salk (1914-1995) developed an inactivated polio vaccine that came into use in 1955, and that was followed by an attenuated oral vaccine that Albert Sabin (1906-1993) had developed in 1961 (Heller, 2008: 6). By the 1950s, "vaccines had become, like antibiotics, a powerful tool in the medical toolkit available to doctors and public health institutions" (Heller, 2008: 66). The elimination of smallpox and the development of the polio vaccine marked a shift in vaccine policies and narratives from the general population to children (Heller, 2008: 20). Canada's last major wild polio outbreak occurred in 1959 and the last case was in 1977 (Mah, 2009: 21). The last cases in the United States occurred in 1979, and the disease was certified eradicated from the Canada and the Americas by 1994 (Mah, 2009: 21; Mnookin, 2011: 55; Offit, 2011: 58). Even so, imported infections have occurred in unimmunized groups. For instance, in 1993, the polio virus was imported to an unimmunized religious group in Alberta (Mah, 2009: 21).

In the 1950s, before vaccination against polio vaccine became widespread, the American National Foundation for Infantile Paralysis (NFIP) recruited about 50,000 children from Alberta, Manitoba, and Nova Scotia into a clinical trial of Salk's vaccine (Smith and Mawdsley, 2011:

89). This clinical trial involved 1.8 million children in the United States and Canada (Smith and Mawdsley, 2011: 99). 24 Polio was an especially feared disease because it caused the paralysis and death of many children. As such, Alberta's residents and officials appeared eager to participate in research that could protect their children and possibly end the risk of polio (Smith and Mawdsley, 2011: 100). In fact, Canadian parents' demands to place their children in this experiment exceeded the need for participants and many volunteers were excluded (Smith and Mawdsley, 2011: 100).

Unfortunately, manufacturing and shipment of the trial polio vaccine occurred without standard quality control and safety checks: "Albertans did not know that in the process of importing the vaccine, the Canadian Federal Food and Drug Directorate's conventional pharmaceutical regulatory role had been bypassed" (Smith and Mawdsley, 2011: 101). Canadian officials instead relied upon safety assurances from Dr. Robert D. Defries (1889-1975) of Connaught Laboratories and NFIP officials (Smith and Mawdsley, 2011: 101). Polio was a seasonal disease and American pharmaceutical companies rushed production because of time constrictions on their efforts to consistently inactivate the virus in their experimental vaccines (Smith and Mawdsley, 2011: 101).

Salk's vaccine was deemed safe in 1955 and came into widespread use, but it remained in its "trial" phase until 1961 (Heller, 2008: 6-7). These trials involved many ethical concerns.

Particularly, parents were inadequately informed of the risks and uncertainties accompanying

<sup>&</sup>lt;sup>24</sup> When an American radio personality voiced concerns about the potential dangers of the Salk vaccine trial, many American parents and the members of the Medical Society of Michigan decided against participating in the trial (Smith and Mawdsley, 2011: 102). The withdrawal of about ten percent of the study's participants created the need to look to Alberta for more children (Smith and Mawdsley, 2011: 102).

their children's participation. In addition, the experimental dose of the Salk vaccine was later found to contain a carcinogen called the simian virus (SV-40 [Smith and Mawdsley, 2011:104]).

Furthermore, there were 120,000 children injected with the live polio virus after Cutter Pharmaceuticals tragically failed to inactivate the virus in Salk's vaccines in 1955 (Heller, 2008: 6-7; Mnookin, 2011: 48; Offit, 2011: 55). As a result, 70,000 children suffered mild polio, there were 164 cases of paralysis, and ten children died (Offit, 2011: 55; Smith and Mawdsley, 2011: 104). At the time of the Cutter Incident, government regulation permitted pharmaceutical companies to withhold notification of manufacturing-related safety issues (Mnookin, 2011: 49). Moreover, the Salk vaccine was successful following two doses, but this was less economical than Albert Sabin's attenuated oral polio vaccination that was successful following one dose (Heller, 2008: 6). Sabin's vaccine caused polio in one of every 2.5 million doses (Offit, 2011: 58). 25 In Alberta, two children contracted polio between 1968-1979 after being immunized with a live vaccine (Government of Canada, 2015: 14). One of the children who contracted polio from Sabin's vaccine was David Salamone, whose father, Dr. John Salamone advocated for sciencebased vaccine safety and was integral in encouraging the USA to switch back to the inactive Salk vaccine in 2000 (Mah, 2009: 21; Offit, 2011: 78-79). Canada stopped using the oral polio vaccine by 1996 after a peak in vaccine-associated paralytic poliomyelitis that occurred in the 1980s-1990s (Mah, 2009: 21).

These controversies resulted in muted counter narratives to the vaccine narrative and they influenced some physicians' uncertainties, and thereby, their practice: "Physicians were devising their own health policies without repercussions: Some counseled against receiving vaccines while others declined to administer them altogether" (Mnookin, 2011: 56). Even so, the

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<sup>&</sup>lt;sup>25</sup> The differences between the Sabin and Salk vaccines are complex. Sabin's vaccine may prevent more children from becoming carriers of the polio disease (see Orent, 2000: 27-28).

Americas were declared polio-free in the 1990s and efforts continue to eradicate the disease globally. Historical narratives overwhelmingly portray polio vaccination and research as an unproblematic solution to a crippling and ever-present danger (Heller, 2008: 8).

Pertussis and the National Childhood Vaccine Injury Act (NCVI)

Vaccine anxieties were high in the early 1970s and 1980s. Parents and some physicians alleged that children had suffered neurological disorders following their vaccination against Diptheira, Tetnus, and Pertussis (DTP). Following the airing of the documentary *DPT Vaccine Roulette*, which was shockingly horrific and inaccurate, parents began refusing the pertussis (whooping cough) component of the vaccine in Britain, and then throughout the United States in 1982 (Heller, 2008: 85; Offit, 2011: 16, 45). Across the USA and other developed countries: "thousands of media outlets falsely alerted parents to the harm caused by the pertussis vaccine" (Offit, 2011: 44; see also Mnookin, 2011: 69).

At the time *Vaccine Roulette* aired, the pertussis vaccine caused more side effects than other vaccinations, most of which were transient, but some of which were serious (Blume and Zanders, 2006: 1827; Heller, 2008: 89; Offit, 2011: 26). Most parents tolerated these side effects while they perceived the risk of the pertussis virus to be substantial, but this changed in the 1970s with the allegations of permanent brain damage (Blume and Zanders, 2006: 1827). Nevertheless, *Vaccine Roulette* showed children suffering permanent epilepsy and/or mental disability. Contrary to scientific evidence, the documentary claimed that the DTP vaccine caused these disabilities (Offit, 2011: 28). Physicians on *Vaccine Roulette* stated their opinions about the vaccine, even when vaccination was beyond their expertise. Notably, however, several

<sup>&</sup>lt;sup>26</sup> DPT was meant to stand for the Diphtheria, Tetanus, and Pertussis (DTP) vaccine.

physicians claimed that Lea Thompson, who produced *Vaccine Roulette*, edited their statements to support allegations the vaccine was harmful (Mnookin, 2011: 71; Offit, 2011).

Nonetheless, in the 1970s, prior to *Vaccine Roulette*, some physicians in several countries questioned universal vaccination against whooping cough because of side effects (Blume and Zanders, 2006: 1828). Their professional uncertainty overlapped with public anxiety in several countries. In response, Sweden suspended the vaccination after uptake rates dropped from 90% to 12% between 1974 and 1979. Likewise, in 1979, after uptake in Japan dropped from 80% in 1974 to 10% in 1976, the country suffered a serious whooping cough epidemic (Blume and Zanders, 2006: 1828). The controversies regarding the pertussis vaccine led several countries to adopt an acellular version of the vaccine, which was less effective and caused fewer side effects. Due to the lowered efficacy of the newer pertussis vaccine, Canada and some other countries experienced whooping cough outbreaks (Blume and Zanders, 2006: 1830).

Vaccine anxieties in the USA intensified in 1986 with the creation of the National Childhood Vaccine Injury Act (NCVI) and the Vaccine Adverse Event Reporting System (VAERS) in 1990 (Mnookin, 2011: 148). At the time, parents were anxious that vaccines were causing harm to children's cognitive development. The NCVI was a response to widespread vaccine-related concerns, such as parental allegations that the mercury-based preservative (thimerosal) caused developmental delays. The NCVI established the National Vaccine Injury Compensation Program (VICP) in 1986, which awarded parents compensation for children's health problems that appeared to be correlated to vaccination (Glassner, 1999: 175-176). The NVICP awarded supposed vaccine victims (primarily from the DTP vaccine) without scientific evidence of causation (Mnookin, 2011: 179; Offit, 2011: 21-22). Injury claims became more difficult to win by late 2004, when this program responded to 4,321 claims linking autism to MMR by

addressing "general causation" theories before seeing to each individual case (Mnookin, 2011: 180). Nevertheless, these court cases provided temporary legal support for allegations that vaccinations carried immense risks. Furthermore, some physicians from various specialties appeared in court as expert witnesses who supported claims that vaccines caused damage. Their testimonies demonstrated professional support of vaccines is not unanimous.

# Measles, autism, and ongoing concerns

The controversy surrounding the measles, mumps, rubella (MMR) vaccine frequented media headlines in the late 1990s and early 2000s. It was—and to some extent still is—a high-profile example of public engagement with science and technology (Poltorak, Leach, Fairhead, and Cassell, 2005: 709). In 1998, the public was prepared to accept Wakefield and colleagues' (1998) claims that linked autism to measles, and thereby, the measles vaccine because of recent incidents involving vaccines. For instance, in 1992, British officials withdrew the two most widely circulated brands of the MMR vaccine once research demonstrated that it caused mild meningitis in 1/6000 or 1/11,000 cases (Mnookin, 2011: 99). The meningitis was very mild and caused few problems, but found substantial media attention and some parents panicked. Some parents sought litigation, vaccination rates dropped, and measles infections in Britain rose (Mnookin, 2011: 99-100). Furthermore, in the USA, in the late 1990s, the Centers for Disease Control and Prevention (CDC) and the American Academy of Pediatricians (AAP) recommended the removal of thimerosal from childhood vaccines without evidence of harm associated with the mercury-based preservative (Mnookin, 2011: 6). Widespread vaccine anxieties existed when Andrew Wakefield's (b. 1957) and similar problematic research appeared in medical journals (Leach and Fairhead, 2007: 45).

Vaccination rates dropped to under 80% in the early 2000s in Britain and measles outbreaks have occurred in various countries (Crompton, 2015: 24; Petts and Niemeyer, 2004: 8; Skea, Entwistle, Watt, and Russell, 2008: 1383). Even so, Britain raised its MMR vaccination rate to an all-time high of 92% by 2008 (Crompton, 2015: 24). In Alberta, in the 2010s, vaccination rates for measles, pertussis, and other diseases were lower than necessary to maintain population immunity (Matkin, Simmonds, and Suttorp, 2014). As a result, the province experienced numerous outbreaks, which were linked to the spread of disease from outbreaks in the Netherlands, the USA, and other locations. That is, MMR vaccination rates remained lower than necessary to maintain immunity after the Lancet retracted Wakefield and colleagues MMRautism article in 2010 and after Wakefield lost his medical license (Alaszewski, 2011; Godlee, Smith, and Marcovitch, 2011; Leask and Fairhead, 2007: 83). The study was initially published in 1998 with numerous methodological errors and appeared to be fraudulent (Alaszewski, 2011; Godlee, Smith, and Marcovitch, 2011). It was a case series, which is a useful method to generate hypotheses that further research often disproves (Mnookin, 2011: 110). The study relied on parental observations of their own children for data rather than objective measurements (Mnookin, 2011: 111; Prior, 2003: 51). Moreover, children's behavioral problems began prior to the Irritable Bowel Disorder (IBD) symptoms that he had claimed caused those problems (Leask and Fairhead, 2007: 45).

After the medical profession disbarred Wakefield, the media "began churning out stories about how a maverick doctor was trying to protect innocent children from corrupt politicians and a rapacious pharmaceutical industry" (Mnookin, 2011: 5; see Leask and Fairhead, 2007: 83). In 2002, BBC-TV aired Wakefield discussing the (nonexistent) link between autism and MMR, but the program ignored Wakefield's removal from the medical register (Mnookin, 2011: 162).

These stories offset scientific evidence against Wakefield's findings because people can maintain popular understandings of risk without scientific evidence and because vaccine programs rely on social support (Beck, 1992: 32; Chen, 2005: 41).

Many studies have demonstrated that media, especially online media, tends to over represent potential, theoretical, and impossible side effects from vaccination (see Bean, 2011; Kata, 2010; Leask and Chapman, 2002). Media coverage has often presented two competing perspectives for and against vaccination without evaluating the validity of each side (Hilton et al., 2010: 944).

Lindsay Prior (2003) argued that Wakefield lacked expertise in the field of immunology and vaccinations, but that his work created the appearance of legitimate evidence of risk (p. 52). Once experts have gained their credentials, the public often cannot evaluate the validity of their claims because only professions have the expertise to evaluate the uncertainty, risks, and safety associated with their actions (Beck, 1992: 234). Prior (2003) labeled Wakefield a "lay expert" whose knowledge in the specific area of vaccination was non-expert (unlike his medical research and knowledge about his own specialty, surgery). Yet, due to his medical degree and media attention, the public received Wakefield as an expert rather than a scientific heretic (Prior, 2003: 53). Wakefield's claims remain relevant to how many parents interpret the MMR vaccine. For example, an Albertan poll of 2,838 people found that one in five of them believed that vaccines might cause autism and an episode of CBC's *Marketplace* demonstrated that many passers-by in a park in British Columbia had similar uncertainties about vaccine safety (CBC, 2014; Southwick, 2015).

Furthermore, Wakefield's claims have endangered children indirectly through parents refusing vaccines and directly through the dubious treatments that he offered for autistic children. Along with Arthur Krigsman (now former physician), Wakefield preformed therapeutic

endoscopies on developmentally disabled children. Wakefield and Krigsman founded Thoughtful House in 2004 with the help of several hundred thousand dollars raised by Liz Birt (1956-2005; founder of Medical Interventions for Autism [MIA]) and \$1 million donation from Jane Johnson and her husband in Austin Texas. (Johnson is an anti-vaccination author and an heir of Johnson and Johnson [Mnookin, 2011: 238]). Both physicians experienced subsequent problems with medical boards and employers (Mnookin, 2011: 235). Even so, Wakefield continues to purport his claims and present himself as a martyr for his cause. For example, he published, *Waging War on the Autistic Children: The Arizona 5 and the Legacy of Baron von Munchausen* (2012) and *Callous Disregard: Autism and Vaccines: The Truth behind a Tragedy* (2011). Moreover, Wakefield finds support and his followers spread his risk assessments through social networks (see for instance, there is a website called "We support Dr. Andrew Wakefield," which is only accessible to users with an existing username and password [see http://www.wesupportandywakefield.com/]).

Other physicians have gained notoriety for questioning vaccine safety. For instance, David Kirby wrote *Evidence of Harm—Mercury in Vaccines and the Autism Epidemic: A Medical Controversy* in collaboration with Registered Nurse Lyn Redwood, who co-founded SafeMinds (Mnookin, 2011: 206). Likewise, "Dr. Bob" (Robert Shields) is a pediatrician whose vaccination experience involves treating individual patients and writing a book recommending an alternative untested vaccination schedule (Cassell et al., 2006: 785; Offit, 2011: 174, 187). Soon after the publication of Dr. Shields's recommendations to delay certain vaccinations in his book, *The Vaccine Book: Making the Right Decision for Your Child*, there were several different childhood disease outbreaks in the US (Offit, 2011: 186). Dr. Shields's claims resonated with Wakefield's

comment that separate antigens may be "safer than the current combined vaccine, although it lacked an evidence base" (Leask et al., 2006: 7243; see also Casiday, 2007: 1060).

To a much lesser extent than these physicians, other professionals often include some subjective and personal knowledge in their understandings of risk. For example, Deborah Gust and colleagues (2008) surveyed over 1,200 physicians and found some recommended against all vaccines and placed greater trust in the Internet and magazine stories for vaccination information than those who recommended patients receive vaccines. Physicians who recommended vaccination, however, stated that the most legitimate information sources included medical journals, other physicians, and government health agencies (Gust et al., 2008: 578).

Given these differences in professional opinions, some parents may refuse vaccination due to confusion. Mike Poltorak, Melissa Leach, James Fairhead, and Jackie Cassell (2005) found immunizers and non-immunizers share many views; despite the distinctions other studies frequently draw between them (p. 711). Such similarities exist because people's responses to risks often involve knowledge that they are mediating between different perceived risks even if one option is incredibly safe:

They may not have expressed their criticism or dissent in public form, but that does not mean they were not chronically mistrustful of, skeptical of or alienated from those institutions supposed to be in control. They may simply have been resigned to dependency on that institution or political nexus, with no perceived power to influence it or make it more accountable (Ritter in Beck, 1992: 6).

Many of those who accept vaccination still have some uncertainties about some vaccine narratives. Often, those without uncertainties about vaccination suspect the media, trust professionalism, travel to poor countries, resist "reading into things," and accept the MMR/autism link as one of many uncertainties and risks (Poltorak, Leach, Fairhead, and Cassell, 2005: 713).

Uncertainty regarding medical treatments is spreading with the growing awareness of these issues. Indeed, the "demonopolization of scientific knowledge claims . . . science becomes more and more necessary, but at the same time, less and less sufficient for the socially binding definition of truth" (Beck, 1992: 156). As such, medical and public health professionals promoting vaccination face various obstacles when discussing uncertainty and risk with their patients. Vaccine anxieties reflect widespread dynamic problems with healthcare information and policies (Glassner, 1998). Stuart Blume (2005) suggested popular vaccine uncertainties receive scant attention in comparison to their extreme manifestations, which researchers depict as anti-vaccination social movements. He argued that the label "social movement" blinds researchers from topics that could best explain the issue at hand—trust in medical professions, pharmaceutical companies, conspiracy theories, communal responsibilities, parental freedoms, and the ongoing process of the health-related decisions that parents make for their children (Blume, 2005; see also Cassell et al., 2006).

#### Conclusion

Similarities between past and present anti-vaccination and vaccine narratives transform, reform, and/or re-emerge within a complex and dynamic social environments. Because medical professions did not explain how vaccination worked during early vaccine controversies, early vaccine anxieties relied on non-scientific evidence of harm (Heller, 2008: 35). Conversely, modern vaccination acceptance, resistance, and noncompliance are veiled in scientific jargon even when the alleged side effects have no scientific basis (i.e. the supposed link between autism and the MMR vaccine).<sup>27</sup> Some authors (especially public health commentators) link previous

<sup>&</sup>lt;sup>27</sup> Some non-scientific opposition to vaccination remains. For example, some parents oppose the norm of immunizing infants and children for diseases that they believe are sexually transmitted (such as hepatitis B or human papillomavirus [see Casper and Carpenter, 2008; Mays, Sturm,

and modern anti-vaccination "movements" without acknowledging vaccine refusals that are based in uncertainties. In doing so, they avoid analyzing how parents and health professionals navigate conflicting narratives, emotions, and perceptions of risk (Blume, 2005: 629; Wolfe and Sharp, 2002).

Many medical-based researchers attribute non-vaccination to misinformation that health departments can correct by disseminating scientific information (Poltorak, Leach, Fairhead, and Cassell, 2005: 710). Unfortunately, public health's "narrow, risk-based framings" often ignore common concerns about vaccines (Poltorak, Leach, Fairhead, and Cassell, 2005: 711). With the wealth of scientific evidence now available to support the dominant vaccine narrative, space exists for discussion with parents and patients. Poltorak, Leach, Fairhead, and Cassell (2005) recommend replacing one-way information delivery with dialogue between parents, health care professionals, and public health officials (p. 718). What can get overlooked without such dialogue is how those who have extensive education about vaccination perceive the treatment. For example, Jennifer Reich (2014) found that mothers who forgo vaccination for their children have conducted extensive and thorough research, but that they value information about vaccines that is based in pseudo-scientific and non-medical perspectives.

In addition to these communication barriers, the status of the medical professions appears to be losing authority. For instance, healthcare consumerism is on the rise, communicable diseases rarely emerge (and when they do, they are often isolated to under vaccinated communities), "lay expertise" is gaining legitimacy among patients, complementary and alternative medicines are gaining popularity, and anti-vaccination advocacy is rising (Ernst, 2002; Leask et al., 2006: 7238; Prior, 2003). These changes compound the discomfort some patients (including some

and Zimet, 2004; Offit, 2011: 67]).

health professionals) feel regarding the rationalistic and nearly militaristic healthcare understandings that medicine emphasizes (i.e. "the war against cancer"). <sup>28</sup> Indeed, previous breaches of trust tainted some patients' relationships with medicine and health professionals. With vaccination, some medical professionals have hidden controversies and dismissed patients' concerns, some bureaucrats have regulated parenting, and some pharmaceutical producers have been profit driven rather than health driven (Leask, Chapman, Hawe, and Burgess, 2006: 7238).

Focusing on the information that parents process tends to also place the blame for vaccination refusals on mothers, who usually make family healthcare decisions, and legitimizes ongoing efforts to correct patient misinformation without addressing broader healthcare issues. That is, the focus on the mistakes that parents and anti-vaccine proponents make when refusing or opposing vaccination maintains a simplified vaccine narrative, which constructs those who accept vaccines as normal, or "the good guys," and those who refuse as abnormal, or "the bad guys." Rather than continue analyzing vaccine anxieties within this narrative, it is possible to use them to observe broader issues in healthcare and to begin pursuing effective solutions to a problem that has existed for centuries (see Bazylevych, 2011).

This chapter sampled controversies surrounding immunization from the use of smallpox inoculation until when the measles and pertussis vaccines largely controlled those diseases in North America. Uncertainties about immunization have existed throughout the history of vaccination and inoculation because these treatments came into use prior to scientific explanations of immunity. Historical accounts of these uncertainties tend to wash over the ambivalence and opposition that some physicians expressed prior to the incorporation of germ

<sup>&</sup>lt;sup>28</sup> Medicine is not only militaristic in its battles against diseases, but it has a strong and often overlooked history of links to the military. For information about military legacies within medicine, see Kutcher, 2009.

theory into dominant understandings of medical knowledge. In fact, the initial popularity of the smallpox vaccine spread largely through narratives about that vaccines efficacy rather than strictly through the encouragement of government or medical authorities.

Opposition to inoculation and early renditions of the smallpox vaccine emerged predominantly from the poor and working classes, irregular physicians, and occasionally, mainstream physicians (Blume, 2005; Kitta, 2012). The dominant voices opposing vaccination changed after vaccination became scientifically explainable, widespread, and demonstrated its success. The eradication of smallpox is one of medicine's greatest success stories, and it resulted in widespread support of vaccination (Heller, 2008), but opposition from middle and upper classes, some alternative practitioners, and a minority of medical professionals remained. Although heavily vocalized, ambivalence about vaccination is much less extreme and less widespread than in previous decades and centuries.

In fact, most people have forgotten or never knew about the vaccine incidents that may have created the most dangerous situations for children (e.g., the Cutter incident with the polio vaccine). Alternatively, uncertainties that have been proven unfounded have maintained momentum in part through narrative (e.g., fears surrounding the pertussis component of the DTP vaccine and allegations that the measles component of the MMR vaccine cause autism). The prevalence of these narratives likely reflects widespread skepticism and uncertainty in medicine. This skepticism and uncertainty seemed to influence the narratives that health professionals shared with me regarding vaccine risks, how they manage uncertainties, their own professionalism, and popular narratives that their patients believe. The remainder of this dissertation reflects upon my interviews with physicians and nurses regarding uncertainties about vaccination.

## **Chapter Four**

"Again it's risk-benefit:" Pharmaceuticalization, government regulation, and patient advocacy

#### Introduction

While I gathered data for this project, I noticed the large number of advertisements encouraging university students and the general public to receive vaccines. Posters at the University of Alberta displayed a student dressed as a knight who was protecting others by complying with vaccination recommendations. Advertisements on Edmonton Transit System buses portrayed newspaper articles from the late 1940s and early 1950s about outbreaks of viruses, such as rubella and polio. These advertisements included the message "keep the past where it belongs." These posters represented the Canadian government's efforts to achieve the "greatest benefit for the least cost" (PHAC, 2006a: 17). Overwhelmingly, the professionals whom I interviewed expressed trust in medical research and government guidelines, but some uncertainty and risk perception emerged in relation to the role of the pharmaceutical industry, and occasionally to the government's vaccine schedule.

Similar to Cass Sunstein's (2002) explanation of Cost Benefit Analysis, which involves weighing the costs of different courses of actions against their expected benefit, Canada's federal government discussed its willingness to incur the expense of certain vaccines: "Some newer vaccines result in health benefits but do not save costs. The decision to include these vaccines in vaccination programs depends on the willingness of society to pay for the health benefits" (PHAC, 2006a: 17). Health professionals may make vaccination recommendations to patients in relation to these government programs. They make these recommendations to patients based on personal risk assessments rather than government guidelines.

Indeed, previous research has demonstrated that many health professionals fall between viewpoints that wholly support vaccines or those that doubt their safety. For instance, Mike Poltorak and colleagues (2005) observed that some health professionals in their study refused some vaccinations (p. 713). Benjamin Levi's (2007) research revealed that residents often held inaccurate beliefs about vaccines. Deborah Gust and colleagues (2008) found that vaccination uptake varies from 51% to 97% among specific practitioners (p. 574). In their survey, physicians who were sceptical of vaccinations often responded with "neutral" or "agree" to statements that there are some risks with vaccination (Gust et al., 2008: 580). Nonetheless, they found that the vast majority (89%) of paediatricians and family doctors whom they surveyed recommended all vaccinations for children. These studies and others have established variation in health professionals' perceptions of the risks associated with vaccine risk and acceptance (see also Dubé et al., 2011: 3178-3179; Loulergue et al., 2009: 4242-4243; Smailbegovic, Laing, and Bedford, 2003).

For instance, Maryna Bazylevych (2011) found that Ukrainian healthcare providers bend immunization policies as they navigate media scares about vaccination, parents' anxieties, public health officials' insistence on vaccine necessity, and their own professional knowledge (Bazylevych, 2011: 438). She explained that during its existence the Soviet Union had provided extensive vaccine coverage to demonstrate how it cared for residents in states such as the Ukraine, which experienced housing and food inequalities (Bazylevych, 2011: 440). As a socialist state, it placed public health above the individual. After the collapse of the Soviet Union, however, many healthcare providers associated vaccines with the free market and pharmaceutical companies (Bazylevych, 2011: 444). Many of the physicians who Bazylevych (2011) interviewed distrusted state officials, disagreed with campaigns against measles and

rubella, or distrusted vaccines made in non-white countries such as India (Bazylevych, 2011: 447-451). Bazylevych (2011) demonstrated that some Ukrainian health professionals doubted state vaccine policies and were ambivalent about their role as "workers of the state" (Bazylevych, 2011: 449).

Notably, Maryna Bazylevych (2011) found that some physicians in her study measured the risks of vaccination differently than Ukrainian government CBA. She found that some recommended against some vaccines for children with specific ailments, especially immunocompromised children. Maryna Bazylevych (2011) found that the physicians whom she interviewed associated some vaccines with the free market and pharmaceutical companies' financial motivations. Similarly, some of my interviewees were concerned about the role of the pharmaceutical industry on the government's vaccine schedule and findings in medical research.

In Alberta, health professionals are "workers of the state," who attempt to guide individuals' decisions about population-based treatments based on their perception of the risks and benefits of vaccines. Rather than seek 100% acceptance like the Ukraine, Albertan health professionals are expected to educate patients who then make informed decisions about their personalized understandings of health risks and benefits. Albertan health professionals presented less doubt in vaccines, than the Ukrainian physicians who Bazylevych (2011) interviewed. In fact, many of the professionals whom I interviewed expressed more concerns about access to vaccines than uncertainties about vaccine efficacy or safety. Financial costs were a prevalent concern when interviewees discussed the costs of vaccines that were available to patients for a fee. Most health professionals perceived the risks of vaccinating to be inconsequential when compared to the risks of refusal. Nonetheless, some questioned the research backing vaccines, the role of pharmaceutical corporations, or government policy. In doing so, interviewees highlighted the

possibility that the government was allowing for unnecessary risk by failing to cover some vaccines or that pharmaceutical companies were gaining too much influence over medicine.

In this chapter, I review how interviewees accounted for the costs and benefits of vaccines in relation to medical progress, pharmaceutical interests, and government guidelines. Some physicians whom I interviewed voiced concerns that some new vaccines primarily serve the financial benefit of large pharmaceutical corporations with limited benefit to the patient. (The nurses whom I interviewed only expressed concerns that they held prior to their professional training, but they acknowledged that many of their colleagues still had vaccine-related concerns. Because I only interviewed three nurses who worked outside of Public Health, I believe my sample of nurses was biased towards those who wholly trust vaccination.) Some physicians argued that they advocated for patients in ways that could conflict with pharmaceutical interests. In doing so, some professionals implied that medical progress should be questioned and that it could have unforeseen risks and costs. In what follows, I first review medical progress and pharmaceuticalization. Second, I discuss how interviewees expressed concerns about government vaccine schedules. Third, I examine how many vaccine-related concerns revolved around the role of pharmaceutical corporations.

### Medical progress, pharmaceuticals, and risk

Although health research generally aims to improve patients' lives, medical progress is shaped by social forces and it can have unforeseen consequences.<sup>29</sup> Indeed, Kuhn (1962) explained that scientific progress is:

<sup>&</sup>lt;sup>29</sup> One extreme example is the total body irradiation experiments that Dr. Eurgene Saenger conducted between 1958 and 1972 without any expected health benefits to the patients (Kutcher, 2009). Saenger was scrutinized heavily because his work appeared to *progress* military knowledge of the toxicity of radiation rather than to pursue effective means to battle cancer. During Saenger's career, other physicians conducted similarly harmful studies with intentions

a process of evolution *from* primitive beginnings—a process whose successive stages are characterized by an increasingly detailed and refined understanding of nature. But nothing that has been or will be said makes it a process of evolution toward anything (pp. 169-170).

Scientific progress, as commonly understood, implies the expansion of knowledge. Furthermore, no universal rules exist for evaluating scientific knowledge, which means that scientific discoveries fail to transcend "the ravages of temporal, cultural, and linguistic change" (Kuhn, 2000: 75).<sup>30</sup> The result could improve people's lives, but it could produce increasingly detailed knowledge that fills other roles. For example, it could build knowledge for its own sake, it could increase corporate capital (Light, 2010: 15), or it could expose uncertainty in areas once thought to be well understood (Douglas and Wildvasky, 1982: 63). Medical progress occurs in relation to surrounding social conditions, including the financial interests of the pharmaceutical manufacturers that conduct much medical research.

Moreover, it is impossible to know every possible outcome from an intervention, and as such, regulatory agencies promote interventions with incomplete or partial evidence. Cass

that were more—although not entirely—grounded in patient care because they received funding from the Department of Defense, Atomic Energy Commission, and the National Cancer Institute (Kutcher, 2009: 73-86).

Similarly, the term "vaccination" has come to mean something entirely different from "inoculation with the material of cowpox" (Marcovitch, 2005: 752; Reidel, 2005: 24). Without acknowledging the changes in the term "vaccination," which now implies extensive scientific understandings of immunity, historians can overlook what early vaccinators understood about the treatment

<sup>30</sup> Kuhn (2000) refined his philosophy of the history of science to include the concept of incommensurability. Incommensurability is a mathematical term, which means "no common measure" (Kuhn, 2000: 58). With this concept, Kuhn (2000) clarified that it is impossible to evaluate older scientific theories without learning the scientific language and methods from the time those theories were dominant. For example, "gold" once meant malleable yellow metal, whereas it now implies a substance with the atomic value of 79 (Kuhn, 2000: 79). Based on the information that accompany knowing the atomic value of gold, readers of older scientific texts may find them nonsensical. That is, assigning the atomic value to gold shifted rather than progressed understandings of the definition of "gold" (Kuhn, 2000).

Sunstein (2002) argued that the costs of researching safety are a factor with any intervention or regulation: "the costs of investigation and inquiry are never zero; in fact, they are often very high" (p. 142). These costs include the financial cost of delaying regulation, the financial burdens of research, and the costs of forgoing that regulation's benefits for whatever time is needed to conduct research (Sunstein, 2002: 142-143). Safety is always "a matter of degree," which means that we know best options rather than guaranteed outcomes. As Donald Light (2010) explained, "To say that new drugs are 'safe' is misleading. When any drug is approved [by the Food and Drug Administration], the most one can say is that it is 'apparently safe based on partial information" (p. 7).

Along with the inability to know everything, patients and health professionals often misinterpret available data. Gerd Gigerenzer (2003) found that physicians' opinions of what constitutes informed consent vary wildly. Rather than "informed consent," Gigerenzer (2003) emphasized "shared decision making," which could consider the patients' perspective and the degree to which the patient desires guidance (p. 96-98). He found that many health professionals emphasized informed consent as though they were deciding between a treatment with *certain* outcomes or refusals with known *risks* (Gigerenzer, 2003: 99). In this way, he explained that physicians maintain an illusion of certainty and avoid informing patients that they are deciding between different risks (Gigerenzer, 2003: 100). With vaccination, these risks may seem trivial or inconsequential. Yet, patient awareness that risks exist may limit their willingness to trust health professionals' accounts that deny such risk. Furthermore, even well-intending physicians may misinterpret data themselves, patients may gather outside information, or patients may misinterpret the information that physicians provide (Gigerenzer, 2003: 105, 114).

As such, public understandings of vaccines and awareness of the limitations of medical research can have implications for their perceived safety. People know that pharmaceutical corporations manufacture drugs with financial interests, including vaccines. Along with some excellent new pharmaceuticals that emerge each year, many new pharmaceuticals offer limited benefits over their often less risky predecessors (Light, 2010: 1). In 1998, adverse drug reactions ranked the fourth highest cause of death in the United States (Light, 2010: 2). Both the rate at which physicians prescribe medications and the rate of adverse drug reactions increased much faster than the rate of illness in the late 1990s and early 2000s (Light, 2010: 2, 4-5). Drug reactions may be more common with pharmaceuticals other than vaccines, but they could alarm many sceptical members of the public.

Light (2010) labeled the "institutional problems" with pharmaceutical regulation "the risk proliferation syndrome," which included the practices, laws, and rules that allow for new pharmaceuticals to be promoted at growing rates, with increasing risks, but with limited potential benefits (p. 15). Light (2010) listed five problems that could manifest in pharmaceutical uncertainty and risk. These problems included: 1) pharmaceutical companies test their own products as a measure to determine safety; 2) reviewers have inadequate time to assess available data about a product; 3) pharmaceutical companies mass market new products when safety is incompletely established; 4) pharmaceutical companies provide incentives for physicians to use their products for unapproved purposes; and 5) institutional practices continue to create new diseases, which then need to be treated (Light, 2010: 15). Unlike Cass Sunstein's (2002) findings that government bodies over-regulate many perceived risks, Light (2010) found that risks from pharmaceuticals appeared to be accepted readily by policy makers and possibly the public.

Some of the health professionals I interviewed expressed uncertainties that overlapped with the problems that Light (2010) identified. Some were uncertain about newer vaccines. They demonstrated suspicion that the products had been incompletely researched or researched with a conflict of interest (points 1 and 2). Kian voiced the strongest reservations. He expressed concerns about both pharmaceutical company influence and the state of research when he discussed vaccination against pneumonia:

I'm not necessarily convinced of the vaccinating for all the strep-pneumonia serotypes. There's some evidence that suggests different serotypes become more prevalent in response to vaccinating against other ones. So, I'd need to see more research on that before I'd be totally convinced. I have huge issues with pharmaceutical influence in drugs and vaccines.

Although Kian spoke more openly of his reservations than most physicians who I interviewed, he emphasized the importance of vaccination in general. In fact, Kian was the only interviewee who shared stories with me about convincing patients who claimed to religiously oppose vaccination into accepting it.

They expressed concern about expensive vaccines and vaccines that are heavily marketed to patients—such as HPV (partially funded at the time), Zostavax (unfunded), and influenza (fully funded, point 3). For instance, a family physician, Nisa, expressed concern that Zostavax could be incompletely researched. She stated that if she trusted the government to provide effective vaccines, then she was unsure why patients have to pay for that vaccine: "I wonder about efficacy of the Zostavax, how efficacy how effective it is given that we have a few—just few years of experience with it.... I think public health would be offering it." Despite Nisa's concern that some patients may pay for ineffective vaccinations, she stated that she would recommend Zostavax to patients who may undergo immunosuppressive treatments in case it offered them some protection.

Interviewees expressed limited concern about point 4 (above) in relation to vaccines about whether the pharmaceutical industry was encouraging physicians to overly promote medication. Even so, some questioned whether the HPV vaccine coverage should include patients who had previously tested positive for HPV.<sup>31</sup>

Finally, rather than creating new diseases (point 5), some physicians were concerned that pharmaceutical companies were creating vaccines for diseases that they believed to be low risk. That is, they believed that some diseases were inconsequential when compared to the costs of vaccination—usually the financial costs. The financial cost of vaccines appeared especially relevant when the patient had to pay the bill. For example, rotavirus vaccines have been provided to six-to-eight-month-old children whose pay under \$200 for the treatment (Weeks, 2013). The Zostavax vaccine runs between \$100 and \$150 in Alberta, but offers limited protection against developing shingles (CBC, 2015c). Similarly, the recommended three doses of the Gardisal® HPV vaccine costs hundreds of dollars (about \$200 per dose for individuals, but \$70 to \$90 per dose for school boards [Ruryk, 2015]). Naomi, a family clinic nurse, explained that the HPV vaccine could be cost prohibitive to some patients:

it's an expensive vaccine and especially for women in their young 20s early or late teens, who are sexually active and often aren't educated in wearing protection and/or using protection. And, those are the women that we often see after we do pap tests are positive for HPV.

In the above quote, Naomi expressed that the financial costs of the HPV vaccine could bar access to some of those who need it most. Likewise, Nisa's comments about Zostavax demonstrated

<sup>31</sup> The CDC (2016a) suggests that there is no research to suggest the HPV vaccine offers treatment to individuals who test positive for HPV beyond protecting them for strains that they do not have (p. 3).

that even she was unsure about whether the cost of that vaccine was worthwhile for many of her patients.

## The benefits outweigh the risks, but...

Overwhelmingly, the concerns that interviewees expressed revolved around the possibility that patients may misunderstand risks or refuse vaccines due to spurious reasoning. Yet, many acknowledged that "safe" implies at least a minimal degree of risk (Sunstein, 2002: 11). They expressed occasional doubts about how government policy was backed in Cost-Benefit Analysis (CBA), and a few recognized the possibility of major complications. For instance, Ren explained that one patient developed encephalopathy and consequent disability after the MMR vaccine, which he argued was a "measure of healthcare" for the population, but a "disaster" for that patient). Some interviewees explained that specific vaccines were either unnecessarily included in Alberta's vaccine schedule or were inadequately covered by the government.

Some interviewees acknowledged that risks from vaccination were possible due to unforeseen issues, but rare. One Public Health nurse explained that with manufacturing and storage errors, the most prominent risk is that vaccines could lose efficacy:

Not to say that there couldn't be errors, [...] factories have errors. A couple years ago almost an entire year of Hep B supply was just ruined. I mean it was never dangerous [....]. And, it's always on our minds. Safe vaccines [are] incredibly important in our area especially because we're already asking people to take a medicine their baby doesn't need in the moment, so safety is huge (Tori, RN).

Tori elaborated the example she gave could result in patients' perceptions that they were "safe" or protected from hepatitis B when they lacked immunity. As such, the risk Tori identified was the risk that population immunity levels could be lower than they should be following the routine vaccination of a cohort.

Alternatively, Dena, a nurse working in a family medicine clinic, expressed concerns that perceptions of "toxins" resulted in vaccine refusals and risks of outbreaks. Many people believe that "zero" is the appropriate amount of exposure to some chemicals even if research only demonstrates substantial amounts being toxic (Sunstein, 2002: 154). Dena believed that the costs of removing certain adjuvants and additives could be worthwhile because of increasing uptake rates. I asked Dena if she thought vaccines had become safer in recent years and she responded:

Dena: I think that they've made them more safe in taking out a lot of the things that don't need to be in there. So, they've made them more popular with the general public [...]. There's not as many 'toxins' in there as the public views it.

TM: And you're using quotes when you say "toxic."

Dena: Yes, because I don't think that anything that's in there is any more toxic than what we eat or what we do in life.

Dena expressed that earlier versions of vaccines were safe by signalling hand quotations around the word "toxins." She seemed to disregard any potential risks with vaccines, but acknowledged that some vaccine components (e.g., formaldehyde or thimerosal) sound risky to parents who are likely incapable of understanding the nuances of risk analysis (see Gigerenzer, 2003: 15).

Interviewees expressed various concerns regarding the role of the government and pharmaceutical companies in the design of vaccine schedules. Some interviewees were concerned that pharmaceutical companies influenced government policies. Most concerns about government regulation revolved around which vaccines are covered. Conversely, concerns about pharmaceutical corporations involved worries about financial costs and the potential that some diseases were unnecessarily vaccinated against.

## Vaccines, risk, and government

Health professionals overwhelmingly praised Alberta's vaccine program as effective and efficient. They argued that Alberta's vaccine schedule aims to protect the population rather than

procure pharmaceutical companies' interests. Nonetheless, some interviewees were concerned about potential barriers to accessing vaccines, limitations in the vaccine schedule, gendered coverage with the HPV vaccine (Alberta only offered the HPV vaccine to women at the time), and the potential for patients to lose the immunity that they gained from vaccines years ago.

Access to vaccines

In Alberta, the dissemination of vaccines is centralized with public health nurses, who provide vaccines at public health clinics and schools. Many physicians and nurses, especially those in rural settings, claimed that centralization was effective and in-clinic wait times were minimal. Public Health nurses explained that they avoided booking delays with routine vaccinations by contacting new parents well in advance of their recommended vaccination date as per clinic policy. Some urban health professionals, however, suspected that the centralization of vaccinations created access barriers due to booking delays, travel distances, or clinic wait lines. They presented these barriers as generating risk by impacting their patients' compliance with provincial vaccine schedules. For example, they highlighted regulations against physicians providing the flu vaccine to children under nine-years-old as a barrier for some families who assumed that they could vaccinate all their children in one trip to their physician, but discovered that they needed to visit a Public Health Clinic as well.

Likewise, some physicians complained about restrictions on adult vaccines. For instance, some expressed frustration that they were forbidden to update Tdap vaccines for adults unless those adults had a laceration. Nisa, a family physician, explained:

Now my pet peeve is that we don't give Tdap. [...] Like really, if anybody's listening out there, let family docs have their Tdap so we can vaccinate our pregnant ladies, so we can vaccinate our, you know, our teenagers or young adults that need their tetanus.

Nisa problematized this restriction because the vaccines in her clinic expired while some adults paid for the tetanus vaccine in travel clinics, which excluded the diphtheria and pertussis update that she wanted adult patients to receive.

The HPV vaccine and who gets vaccinated

Some physicians stated suspicions of vaccine research and efficacy, particularly for vaccines that are/were omitted from Alberta's immunization schedule. Similarly, Mamo and Epstein (2014) critiqued the role of the pharmaceutical industry in the marketing of the HPV vaccine and Heptavax B (HBV vaccine against hepatitis), which involved the sexualization of cancer prevention. Furthermore, they stated the use of pap-smears in the United States had decreased cervical cancer related deaths by 70% prior to the use of the HPV vaccine (Mamo and Epstein, 2014: 160).<sup>32</sup> They found that recent marketing of these vaccines more closely resembled marketing practices for other pharmaceuticals than it did for traditional childhood vaccinations (Mamo and Epstein, 2014: 163). Unfunded vaccines generated uncertainty because of interviewees' assumptions that Public Health included effective vaccines in the provincial schedule—or at least in Canadian recommendations. For example, the cost of the HPV vaccine was a major issue concerning financial access barriers, trust in the efficacy of the preventative measure, and counselling female patients who were too old to receive the government provided vaccine, and male patients.

At the time of the interviews, the Alberta immunization schedule only provided the HPV immunization without charge to young women (those in grade nine). These guidelines were changed while I was writing to include young males (Ruryk, 2015). As of summer 2015, Prince Edward Island, Nova Scotia, and Alberta offered the HPV to all genders at the start of the

<sup>&</sup>lt;sup>32</sup> While the actual duration of HPV vaccine protection is under study, research has suggested that the vaccine offers protection for at least a decade (CDC, 2016a: 3).

upcoming school year (Ruryk, 2015). Ontario, Quebec, and Manitoba were in the process of extending coverage to include boys in fall, 2016 (Dehaas, 2016). British Columbia (BC) offers the vaccine selectively to "at-risk" grade nine boys, which generated critical responses (Shapiro et al., 2015). BC defined "at-risk" boys as those who were "vulnerable," "street involved," or homosexual (Dehaas, 2016). Likewise, Saskatchewan only offers the vaccine to HIV positive boys (Dehaas, 2016). BC's decision was controversial. It requires boys to know and share their sexual orientation at a young age, and it could result in the stigmatizing conflation of "at-risk" with homosexual (Shapiro et al., 2015).

Nisa, who is a family physician in an urban center, explained that public funding for the HPV vaccine enables physicians to recommend the vaccine without burdening patients. Then, she shared some apprehension about the HPV vaccine's efficacy for the use of older women:

Usually when public health starts funding it, I think that physicians feel more empowered. We assume that it would have done its research and yes we can give it in boys and yes we can give it in older women. And of course, the HPV again, its efficacy is questionable. Whether everybody should get it is questionable. But certainly, it makes sense in younger populations. In younger children, you know teen children. But of course we have women who don't have HPV abnormal paps who are now recommended to get HPV vaccine [...]. But again, if a ten-year-old has not had an HPV vaccine I would certainly give it to them.

When I asked Nisa if the provision of HPV to only females was concerning, she shared her trust in the CBA backing government policy:

Well I wasn't worried because I know that you need studies, you need enough patient demographics. So, I just thought, I just assumed I mean, I haven't looked at the studies directly, but they had probably not enough men in the studies to recommend it to the men. Not necessarily that it wouldn't work in men, or it's not safe it men, but they just didn't have enough data.

As Nisa elaborated, she expressed ambivalence about the efficacy of the HPV vaccine for specific populations. She accounted for public health policy as a proxy for medical knowledge. Even so, her assumption about the need for data may demonstrate reliance on data that is specific to the country in which she practices. Australia began offering the HPV vaccine to boys a year before our interview.<sup>33</sup>

Likewise, Johanna, an urban family physician, questioned the role of pharmaceutical companies in government decisions to provide the HPV vaccine to males: "It should cover both, but I'm just worried if the [...] pharmaceutical would have a lot of influence on [...] trying to push it for boys too." When I asked if she thought the HPV vaccine was effective, she continued:

Well it's a new vaccine. [...] I'm not that up to date to see if there's any drop in rates. I have kids, boys, and will I give it to them? Mm, not sure. Yeah, I want to see more data before I give it to boys.

Johanna's uncertainty about pharmaceutical companies' influence on vaccine recommendations and the slow expansion of HPV vaccine coverage extended to her own children. Most interviewees preferred over-vaccination when unsure, but some selected specific vaccines that they would consider forgoing.

Waning immunity and vaccine updates

Other interviewees were concerned about population immunity levels. An urban family physician, Kai, expressed frustration regarding what she perceived to be an inadequate effort to keep physicians' knowledge of the vaccine schedule up to date. In addition, she argued that Alberta inadequately updates some children's vaccines and that she is aware of these problems because of her role as a parent, rather than as a physician:

<sup>33</sup> Australia experienced a 61 percent drop in genital wart cases among young women since it initiated an HPV vaccine program in 2007 (Harrison et al., 2014: 5). In February 2013, the Australian government extended this program to cover boys aged 12-13 years (with a two-year

catch up for boys 14-15 years [Harrison et al., 2014: 2]).

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Our pediatricians don't even know what the immunization schedule is. That means that they [Public Health] are not communicating it well. I know some of it because I got kids that are getting immunizations. I was offended and appalled when my son was in grade 9 and I realized he was not getting a booster of chickenpox.

Prior to this statement, Kai expressed concern about vaccine uptake. She associated some of the risk of disease with perceived gaps in the immunization schedule:

But, the biggest issue with the chickenpox vaccine is they're not doing the catch up with the 10-year gap of kids. So, they'll wear off as adults, and there's always going to be some going around because there's enough people who don't vaccinate. So then, we're going to start seeing more adult chickenpox, which is not my idea of fun.

During her interview, Kai cited research to support her acknowledgement of gaps in the immunization schedule. She voiced concern about the government's response to disease outbreaks and with the provincial immunization guide. Unlike some interviewees, however, all of Kai's concerns rested in ensuring patients received enough vaccines to lessen the risk of disease.

For instance, some highlighted the pertussis vaccine as requiring more updates that the province of Alberta often provides. A pediatrician, Tobias, who had practiced with the now outdated whole cell pertussis vaccine in prior years, explained that the newer acellular vaccine may be less effective. As such, he wished to see older patients receive a booster for that vaccine:

Yeah, I think with pertussis it's not as effective as the others, so yeah that's a concern. But, the disease tends not to be so severe when you're older. Although, if older people get it, they spread it around. So yeah, I think having a booster of pertussis--what 18 years or whatever--I think that's a good idea.

Several physicians questioned whether all vaccines were provided with adequate booster shots to ensure lifelong immunity. They were concerned that the province may create unnecessary risk by trying to save the cost of providing older cohorts with ongoing vaccine updates.

## Pharmaceuticalization, risk, and uncertainty

In accounts that questioned pharmaceutical research, physicians aligned themselves with some prevalent critiques of medicine, and more specifically, of pharmaceuticalization.

Pharmaceuticalization involves expanding the pharmaceutical market and promising health through medication instead of any other possible treatments (Williams, Gabe, and Davis, 2008). Pharmaceuticalization differs from medicalization: "Ideally, medicalisation should be considered a value-neutral term that simply denotes the making or turning of something into a medical matter" (Williams, Gabe, and Davis, 2008: 814). Some physicians questioned pharmaceutical corporate interests. They explained that the population was a massive consumer-base and that the government's recommendation or provision of various treatments created the potential for huge capital gains. Even so, the demands associated with their profession often keep physicians too busy to thoroughly research the costs and benefits of the pharmaceuticals that "friendly, generous sales reps" market to their clinic (Light, 2010: 9). Although some physicians I interviewed voiced mild scepticism, they may have limited knowledge beyond the continuing education that pharmaceutical companies often sponsor.

Overwhelmingly, interviewees stated different opinions about vaccines than they expressed about other medications. Nonetheless, some physicians stated that their role involved mediating between pharmaceutical companies that pursued capital gain over population health, and an often-naïve population of healthcare consumers. For instance, Kian, who is a family doctor, explained that moderate scepticism was a responsible approach to patient care. He stated that pharmaceutical interests influence medical knowledge:

A lot of research is driven by pharmaceutical companies, [...] I don't think there's any doubt about that. And medicine is so incredibly conservative. [...] that's a good thing in one way [...]. Medicine moves very, very slowly and it moves in a direction. It's slow to

turn around, right? Medicine has done fantastically well with the germ theory with illness, and it's still very, very, very difficult to move away from that. We've done very, very well with the genetic theory of illness, so it's very hard to move away off of that [....]. And, we have the most incredible array of medications being developed to treat all of these inflammatory illnesses, when quite possibly—I'm not saying this is for sure—there are easier treatments. Since nobody is going deeply into the ideology of these treatments and we're just kind of accepting that nobody knows.

Kian presented himself as sceptical of some aspects of medical science and supportive of the best interests of his patients. Notably, however, Kian recognized that the guiding theories behind medical discourse could change with the progression of knowledge. Kian's comments largely reflected an assumption that medical knowledge had improved, but they also hinted at how Kuhn (1962) explained that scientific knowledge periodically undergo a revolution—or a paradigm shift—which results in the creation of new scientific theories and related practices. Kian referred (in different words) to paradigm shifts in medical science and explained that these shifts continue to happen—germ and genetic theories of disease. By recognizing the potential for such change, Kian acknowledged the possibility that the foundations of his profession could change.

Interviewees were clear that practicing medicine involved far more than pharmaceutical interventions. For instance, some physicians accounted for the various aspects of healthcare they provided that differed from prescribing pharmaceuticals. For instance, Anita, who is a family physician, detailed how she navigated pharmaceuticals, diet, and lifestyle as preventative health treatments:

Treating blood pressure is a preventative treatment and people get that. Smoking—technically you're healthy—we don't want people smoking. So there're things we do. It's not just vaccines we do on healthy people. Ninety percent of a preventative health visit is talking and doing preventative things. Are you drinking too much [...]. And all of the things--technically they're a healthy person. Sunscreen use, wearing sunglasses, getting

your eyes [checked], all these things are in healthy people. And, it's because we're lucky enough that we're not dealing with, you know, the person who has a [blood] sugar of 30 who walks in the office, 'Oh I've never been checked before.' We're lucky that very few times do we have to deal with that. [...] [T]o the healthiest person [we're] saying, 'What can we do to keep you as alive and healthy for as long as possible?' Not everyone gets to do that, and somehow we're spitting in the face of it and saying, 'well we have this amazing thing, but no I'm not going to do it because of x, y, or z is just wrong.' You can tell I'm pro-vaccine.

Anita expressed that the use of pharmaceuticals was *part* of her job. She explained that the use of pharmaceuticals created risks, but that vaccines provided few reasons for concern. In this way, Anita's account constructed her professional role as much more than pharmaceutical promotion and paternalistic decision-making.

Chandra's account of pharmaceuticalization and risk

Pediatrician Chandra evaluated pharmaceutical risks at length in her account of growing public awareness of medical uncertainties and the need for health professionals to adapt. For example, she acknowledged patients' awareness of these uncertainties:

on the side of efficacy there's also the question of commercial interests and for who's good are these immunizations? [...] Is it at the level of the individual? Is it at the level of the public or society at large? And, what is the conflict of interest posed by the companies that produce the immunizations [and] also [are] financially benefiting from the data that supports their efficacy? So, I think that [...] we have an increasingly savvy public. And I think that they are not [...] simply [to be] pat on the head and say, 'There, there don't worry about it.' I think that they worry greatly about it and have cast doubt on the authenticity of the data because of the financial conflict of interest.

Chandra presented herself as a health provider who is responsible to provide patients with information to weigh costs and benefits themselves, and thereby, to make informed decisions. Her respect for patients' decisions positioned Chandra's account within a context that

emphasizes parents' responsibility to make health decisions for themselves and for their children (see Reich, 2014).<sup>34</sup> All interviewees supported patient choice and education over mandatory vaccination even though many constructed vaccine refusal as the wrong choice.

Chandra contextualized her concerns about informed consent and patient safety within a medical profession that is heavily influenced by pharmaceutical manufacturers. She detailed the possibility of unknown risks associated with vaccines before describing her support of vaccines:

If we look back to when I was trained, I don't believe that I had any real knowledge of any serious consequences of immunizations. They are—or at least when I was trained—billed as safe and effective. And, I think not only has their efficacy been called into question, but I think their safety has been called into question, where some things have been spurious. I think the Wakefield type report has been retracted and he has been disbarred [...]. But, not everything is spurious. There are actual real life cases, including with the flu shot of people that have eye disease, [...] or various other kinds of serious health consequences that arise as a consequence of being immunized.<sup>35</sup>

I remember when I was a pediatric resident. I had the opportunity to care for a patient who had developed arthritis in every single joint in her body. And I don't know if you can imagine just how many joints we have. But she was in a constant state of pain. And, that was attributable back to the re-immunization--the booster--she was given in high school. And, she will live with this the rest of her life. So, I think that the safety of immunizations is also worth taking seriously and measuring. And I think in the US they do that with the VAERS [Vaccine Adverse Event Reporting System] program, I think in Canada, again more often than not, there's somehow a cultural disposition to, you know,

medicines.

<sup>&</sup>lt;sup>34</sup> For instance, Jennifer Reich (2014) wrote about privileged mothers' decisions to refuse vaccines. Jennifer Reich (2014) found parents made such decisions for their children through extensive research and investments to provide health conscious food, maintain "safe" social networks, and/or utilized other individual and health consumer products, such as alternative

<sup>&</sup>lt;sup>35</sup> The potential for adverse reactions is constant with vaccination. Research into adverse reactions shows that serious adverse reactions to influenza vaccines are rare (Moa et al., 2016: 4097-4098). Even if unlikely, however, the possibility always exists that some reactions are unreported or are attributed to causes other than vaccination.

pat people on the head and say, 'There, there, don't worry too much about it.'<sup>36</sup> And that's really not [...] very fair in terms of as an approach, because the public and healthcare providers want better quality data. And [they] want better assurances that things in fact are as safe as they've been told [....]. And again, [...] things are calm until you disturb them, but once you disturb them they start to churn. And I think that's the state we're in now, is things are churning. And I think as a result of that, the immunization rates are waning.

Chandra had explained how safety and efficacy concerns weave into public dissent from the vaccine schedule. She argued that the "illusion of certainty"—which Gigerenzer (2003) critiqued and that Sunstein (2002) argued backs most CBA—is an ineffective means through which to encourage patients to vaccinate. Her explanation implied such false reassurances are ethically problematic because they encourage patients to make decisions based on partial information.

I inquired whether Chandra's experience had aroused personal concerns regarding vaccine safety, but she said, "No" and that she remained supportive of vaccines. Her concerns rested more with the quality of information that patients receive, rather than with the regulation of risk:

I think people have a right to informed consent. And I think informed consent rests on good quality data. I think good quality data rests on not having financial conflicts of interest. So, I think it's best if things can be done in an open transparent and rigorous fashion and I'm not suggesting that they haven't been. But that isn't always how they've been packaged. And there's been enough in that, in the way that things have been done that doubts have been cast.

Chandra suggested that conflicts of interest impeded informed consent by creating potentially biased clinical results. Her concerns resonate with another of Gigerenzer's (2002) arguments. He stated that informed consent was only in reach of those with an extensive medical education, but

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<sup>&</sup>lt;sup>36</sup> Canada has an adverse reporting system as well. It is called the Canadian Adverse Events Following Immunization Surveillance System (CAEFISS [PHAC, 2015]). Although CAEFISS exists, there are limitations to any reporting system. Limitations include a lack of standardization to the numerous efforts to report and analyze adverse events, especially regarding minor reactions (such as a skin rash [PHAC, 2015: 92631]).

even those with medical education may misinterpret statistical information. Unlike Gigerenzer (2003), however, who emphasized the potential for people to misinterpret statistics, Chandra cautioned that financial conflicts further cloud understandings of the quality of medical research. *The new, the old, and the risky* 

Interviewees almost universally set aside "older" vaccines as legitimate and necessary treatments, about which (if anything) the population needed more. Alternatively, some interviewees regarded newer vaccines with scepticism about pharmaceutical research. The perception, however, of "new" varied. Some "new" vaccines have been used for over a decade or have been thoroughly researched in non-Canadian contexts. Nonetheless, interviewees accounted for their own suspicions of newer vaccines—regarding influenza, HPV, rotavirus, and varicella—as professional thoughtfulness and critical thinking.

Most of the healthcare professionals I interviewed mentioned subtle uncertainties, which reflect the specialty of their knowledge, rather than any doubt in the necessity of the flu vaccine. For example, MaKenna (who was an RN in Public Health) stated, "I mean, there are newer vaccines that haven't been around that long. So, I guess time will tell about how long effectiveness will last, but I'm still confident in them." Likewise, Anita explained that the flu vaccine is incompletely effective:

Especially this year with how severe [the flu] is, I would say any prevention, even if it gave people the fever and the chills and the feeling crappy for a day, is again risk benefit. Right? It's not a great medication; it's not 100% by a long shot; it's not as great as a lot of our other vaccines. But, if it's all we have, and it's that versus the risks of very young, healthy, perfectly good patients [being] sick and dead, I should say in ICU, that would be where I'd be on that. But it's a case-by-case benefit, so I tell patients, like, that's where we're at. But, of course the one-week where people see this in the news they're flooding in.

Anita's explanation highlighted the difficulty of normalizing flu vaccine uptake. She explained that patients pursued the vaccine when concerned about the virus, rather than when trying to follow vaccine guidelines. Other interviewees, including a surgical nurse, explained that they believed the flu vaccine was necessary and effective, but lacked knowledge regarding minute details (i.e. the strains covered that year or how to advise pregnant women).

As I explain in Chapter Six, several physicians stated that they avoided the influenza vaccine or believed it to be unnecessary. Damian explained that the flu vaccine was considered "fairly untried" for some time:

Well, I suppose professionals who have scepticism about the flu vaccine, obviously, which was considered fairly untried and I was quite sceptical. Yes, I suppose I was quite sceptical of the flu vaccine. But once again I feel ok about it now, I was sceptical of it when it first came out and I didn't like that Alberta Health made it a requirement that people do the flu vaccine, that medical doctors do the flu vaccine. I mean, they couldn't force me to do it, but people that work in the hospital system [...] were suspended from work if they didn't do the flu vaccine.

Likewise, some nurses explained that they were initially sceptical of that vaccine. Although some interviewees highlighted the newness of the flu vaccine, its newness compared to some vaccines they supported is debatable.

The label "new" seemed to emerge from perceptions of the existing literature, government support of a vaccine, and to some extent the passing of time. For example, the pertussis vaccine often was labelled less effective than other older vaccines, but rather than question whether it was necessary, interviewees focused on promoting vaccine updates. Alternatively, the flu vaccine was first recommended for children between six and twenty-three months in 2004. Alberta Health Services only began offering the flu vaccine to the wider public without a fee in recent years. The USA began providing the influenza vaccine to children aged six to twenty-

three months in 2004 and by 2010 it expanded recommendations to include everyone under eighteen-years-old (Hoen et al., 2011: E1025). The Canadian Advisory committee provided similar recommendations as the USA until 2006 when the USA began recommending that vaccine to children aged two to six—Canada waited until 2011 to make the same recommendation (Hoen et al., 2011: E1026). Similarly, HPV was approved for use in Canada in 2006 (CPHA, n.d.), but many interviewees stated it was "new."

Both the flu and HPV vaccines received some skepticism. Nonetheless, nearly every interviewee who mentioned Prevnar expressed strong support for that vaccine. Prevnar is used to prevent pneumococci diseases such as pneumonia. It entered the pharmaceutical market about fifteen years ago, but Canada only began funding it for children under five-years-old in 2009 (Public Health Division, 2010: 1) and to adults over fifty-years-old in December 2014 (Public Health Division, 2014: 2). That is, Prevnar Canada had approved Prevnar more recently than the influenza or HPV vaccine, but interviewees did not mention the newness of the evidence backing that vaccine.

Concerning the general use of vaccines, interviewees explained that their uncertainties about safety were trivial compared to their perception of risks with refusal. For instance, family physician Anita explained that there were some things about vaccines that she could not know, but that she did know the treatment was effective at maintaining health:

Anita: Well, I'm sure there's stuff that we don't know, but again it's risk-benefit. So, my thought would be we have juvenile arthritis and we reasons to have something. And it's like the autism where we say, [...] you know, game over because of Wakefield right?<sup>37</sup> TM: Yup.

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<sup>&</sup>lt;sup>37</sup> Andrew Wakefield was the physician who co-authored an article that the *Lancet* retracted, which linked the MMR vaccine to autism (see Wakefield et al., 1998).

Anita: But [...] the patient I saw with the seizure, will we ever know if it was related to that, or was it just bad timing because you got a cold and, like, you just won't know. But in the end, one person who gets a seizure who in the end is fine or the arthritis, like because I'm also I was reading something about which one was associated with um... shoot,.. was it sleep? There's something going on (TM: oh, the narcolepsy?) The narcolepsy, yes yes yes.

TM: H1N1

Anita: Thank you. The H1N1 right, so if that's associated that really sucks. But again, it's to look at the numbers and see when a patient takes something they're aware [of], and think that if that actually causes that risk and it happens to them, that would really suck, but it would suck more if they got the H1N1, went in the ICU, and then they die. So, numbers in like [...], yes we can allow for a few things that happen with a treatment--we do it all the time. We give someone any medication for blood pressure and we're assuming someone's going to get some type of side effect, right? But they're ok with that. You get much more side effects with the 10 billion medications we give say, 'oh we'll treat 10 people and maybe it'll help 1 or 2,' but somehow we're totally fine with that as opposed to the thousands we help with vaccine and the one person gets affected, the numbers just don't make sense and somehow we're so focused on that, compared with any other aspect of medicine.

Anita explained that patient concerns regarding vaccine safety baffled her. She placed concerns about arthritis and childhood narcolepsy (which had emerged in Canadian news near the time of interview) within the realm of the unknown as she explained the necessity of vaccines.<sup>38</sup> Her explanation involved a slight risk to individual children, which she rationalized by seeing vaccines as protecting both individuals and the population. Likewise, despite any concerns about

<sup>&</sup>lt;sup>38</sup> Several research projects investigated the link between some variations of the 2009 H1N1 vaccine and narcolepsy in Europe. This link was specific to the European versions of the vaccine and was suspected in vaccines containing a similar adjuvant to ASO3, which was present in Pandemrix (CDC, 2013). ASO3 was used in Canada during the 2009-2010 H1N1 influenza pandemic (CTV, 2013).

government regulations or pharmaceutical corporate interests, interviewees overwhelmingly supported Alberta's vaccination schedule.

#### Conclusion

The health professionals whom I interviewed highlighted their concerns regarding access to the vaccines included in Alberta's vaccine schedule and the influence of pharmaceutical corporations on that schedule. The professionals whom I interviewed supported Alberta's vaccination schedule and expressed only minor concerns regarding the validity of the research backing specific vaccines. These concerns are unsurprising, given the findings in previous research.

Even so, the professionals whom I interviewed presented vaccination risks and benefits as similar to what government policies and expert evaluations suggest. That is, vaccines appear to offer the greatest benefit at the lowest cost, although some of them questioned specific vaccine's efficacy or financial cost. Although it is only possible to know safety to a degree (Light, 2011: 7; Sunstein, 2002: 142), experts offer the closest approximation that we can get to the "truth" or "certainty." The ability of experts to approximate the truth is why Collins and Evans (2011) argue that expertise is something that is "real" and substantive beyond what members of the public or more general scientists know (p. 237). Interviewees overwhelmingly referred to those whom they perceived to be experts, such as vaccine policy makers and immunology researchers, when accounting for whatever information was beyond their personal knowledge.

Early medicine included more uncertainty than recent years, and early descriptions of medicine represented it as both an art and science (Gigerenzer, 2003: 88). More recently, medicine has been transforming in relation to the influences of pharmaceuticalization. Indeed, Donald Light (2011) questioned whether pharmaceutical companies had influenced government

vaccine schedules and findings in medical research to promote their products (p. 15).

Nevertheless, while the rates of adverse drug reactions have increased (Light, 2011: 4-5), this is a very minor issue with vaccination. The professionals whom I interviewed appeared to be aware that known risks with vaccines are miniscule and that unknown risks are likely less consequential. As such, they predominantly responded to my questions about vaccine risks by using personal stories that conveyed the importance of vaccines to prevent disease outbreaks or with simplistic explanations that the benefits of vaccination outweigh the risks.

In this chapter, I reviewed how most of the professionals who I interviewed expressed trust in medical research and government guidelines backing vaccination. I explained that vaccination policy and research can be problematic and that many of the health professionals who I interviewed were aware of the potential for some problems. For instance, the Canadian immunization guide is based on Cost Benefit Analysis, which it explains in terms of financial expensive and savings (PHAC, 2006a: 17). Likewise, the pharmaceutical industry influences vaccination research and the direction of medical progress. It follows that this influence could progress medical science towards knowledge expansion for the sake of knowledge expansion or towards financial interests (see Light, 2010). With regards to these expansions, it is impossible to create procedures that are proven to be perfectly safe because of the limitations of research (Light, 2010: 7; Sunstein, 2002). These limitations with medical knowledge and practice appeared through my interviews with health professionals who acknowledged that medical science and practice are imperfect, but emphasized their importance in the maintenance of health.

## **Chapter Five**

# "You must vaccinate your children:" Practicing with medical uncertainty

#### Introduction

When I spoke with physicians and nurses about vaccine uncertainties, they emphasized the certainty that some (if not all) vaccines were essential to public health. As I anticipated, most interviewees attested to trusting the scientific evidence supporting vaccines, yet ambiguity surfaced about specific issues:

Yeah, nurses, lots of nurses are against vaccines and most of it's quasi-scientific--well, all of it I would say. [...] Some of it is [...] a bigger dose of my cautions. So, my own personal cautions about vaccines, if you get too big a dose of that, then you'll turn against them, you know what I mean--you can turn against them completely. [...] If you're like me and you start looking for problems, then eventually you might say, 'Well I think that we should just get rid of them all together.' I think that's very irresponsible because I think that in the present age, you must vaccinate your children (Kian, rural family physician).

Kian shared more awareness of the gaps in his knowledge with me than other interviewees. He articulated the ambiguity surrounding vaccines when he described growing up with parents who refused vaccines and how he carried limited skepticism throughout his career. Then, Kian detailed the potential consequences of vaccine refusals. He provided an example of a patient who "denied his children their childhood vaccines," but also could not ensure his children gained immunity through exposure to "childhood diseases" (i.e. measles, mumps, whooping cough, chickenpox, and so forth). He concluded that his awareness of the gaps in his professional knowledge was similar to the cautions of those who refuse vaccines, and explained that: "being against vaccines [...] can be understandable, but it's irresponsible to say not to vaccinate children" (Kian). As such, he expressed certainty in the form of a narrative moral that families

must accept immunization. Overall, his story epitomized how health professionals can be situated as conveyers of information between vaccine experts and the general public. His professional knowledge reiterated dominant understandings of vaccines and the "vaccine narrative" that accompanied the glimpses at the uncertainties that emerged during interviews with health professionals.

The culturally dominant narrative of vaccines explains how researchers used medical science to protect the body from deadly diseases (Heller, 2008: 22). This grand narrative (and various counter-narratives) play an essential role in vaccination uptake, dissemination, and refusal (see Kitta, 2012). Counter-narratives are small stories that depict vaccines as dangerous, ineffective, or otherwise undesirable (e.g., stories about children becoming autistic following a measles, mumps, or rubella [MMR] vaccine, or various stories about how vaccination against human papillomavirus [HPV] could result in promiscuity). Counter-narratives constantly appear in social media and mass media (Bean, 2011; Hilton et al., 2010; Kata, 2010), but grand narratives remain dominant because most of the public supports vaccines (Heller, 2008). The vaccine narrative, like other cultural narratives, provides scripted meanings that explain an event through narrative structures. Narratives simplify our understandings and hide contradictory information and stories (Heller, 2008: 8). Yet, as my findings suggest, those who buy into the vaccine narrative can also express *uncertainties* including small counter-narratives and contractions.

Those who experience such uncertainties may remain confident in vaccines as they would with many other treatments. Indeed, uncertainties are common to daily medical practice and patient encounters (Schattner, 2009: 76). The history and structure of medical knowledge points to the impossibility of certainty. Uncertainties involve the boundaries of medical science, gaps in personal knowledge, and the limitations of professional training (see Fox, 1959: 238; 1988: 502).

Even so, research regarding medical uncertainty predominantly emphasized topics where uncertainty is undeniable, such as hormone replacement therapy or breast cancer screening (see Gerrity et al., 1992; Gigerenzer, 2003; Griffiths, Green, and Bendelow, 2005).<sup>39</sup> Studies that specifically analyzed vaccine uncertainties primarily involve controversial vaccines. These studies ignore the perforation of uncertainty that can occur in even the absence of doubt regarding the necessity or safety of a procedure (exceptions are Bazylevych, 2011; Chen, 2005). Uncertainty seeps into mundane medical practice, and it remains prevalent even when health professionals adamantly support specific treatments.

I began this chapter with an interview excerpt to emphasize that even with uncertainties, health professionals accepted the grand vaccine narrative. They framed vaccines as necessary, safe, and effective even when they expressed uncertainties and contradictions. Despite these uncertainties, health professionals have ways to reproduce the vaccine necessity. Indeed, uncertainties may be inherent to medical practice, but practically irrelevant to some medical decision-making. As I discuss in the next chapter, health professionals' perceptions regarding the necessity of specific vaccines lacked homogeneity. In this chapter, I demonstrate the management of the uncertainty around a treatment that many interviewees called (in various wording) as simple as vaccines. That is, through various tactics, health professionals constructed their acceptance of vaccines as a simple, taken-for-granted assumption.

In what follows, I first review how my analysis informed this chapter. Second, I describe types of medical uncertainty that are most relevant to this project. Third, I argue that health professionals practice with incomplete knowledge about vaccines and review what I interpreted

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<sup>&</sup>lt;sup>39</sup> Regarding vaccines, resolved examples include the shift from the whole cell pertussis vaccine to the safer although less effective acellular vaccine (see Blume and Zanders 2006; Heller, 2008: 89), and the replacement of the attenuated (live) oral polio vaccine with the inactivated (dead) injection (Heller, 2008: 6; Offit, 2011: 77-80).

to be management tactics within my interviews. The health professionals supported the vaccine narrative through their own stories about their certainty in the necessity of vaccines, their ideas about the benefits and risks of vaccines, and their trust in authoritative knowledge and medical progress. Finally, I discuss how the vaccine narrative and trust in the authority of medical knowledge are necessary but problematic for the provision of vaccines as a preventative health treatment.

## Methodological note

When I began this project, I anticipated that people might hold beliefs that represent gaps and/or contradictions to professional training. This perspective likely emerged during my previous research about alternative religions and health. As such, I understand health professionals to practice based on their training, professional experiences, and personal histories: "It is the lifetime that makes [medical practice] a scientifically informed human art. The results of any procedure on a body can be nearly certain, but because humans are unpredictable as individuals, their bodies may also be unpredictable" (Fieldnotes, 22 August 2013). Three of my assumptions about medical uncertainty are particularly relevant to this chapter. First, even professionals may dissent or differ slightly from the views that dominate their profession (see Abbott, 1988: 61). Second, experiences could compliment or contradict professional training and knowledge. Third, health professionals share somewhat common educational backgrounds, but they belong to diverse social worlds.

Various forms of narratives, including the grand vaccine narrative, are a common means through which to express vaccine beliefs (other examples include such forms as legends and rumours, [see Kitta, 2012: 21]). During interviews, health professionals shared varying beliefs about the risks and safety, efficacy, necessity, and side effects of specific vaccines. Indeed,

counter narratives emerged and were built into a general acceptance of the dominant narrative that *vaccines are safe and essential to health* (see Heller, 2008).<sup>40</sup> Even this dominant narrative, however, varied somewhat in that it referenced either population health or individual (usually child) health.

As per the details in my methodology chapter, this chapter primarily engaged *small stories* and *stock images* from interviews, which were about the importance of immunization and managing medical uncertainty. Small stories describe isolated experiences and events rather than one's life (Squire, Andrews, and Tamboukou, 2008: 7). Many similar small stories entered my conversations with various health professionals. One label for these recurrent small stories and other forms of explanation about vaccine knowledge is stock images. Mary Jo Maynes, Jennifer Pierce, and Barbara Laslett (2008) used the term *stock images* to refer to the similar events that emerge when various people from a similar social position speak about their experiences (p. 81). The majority of stock images and small stories that I analyzed depicted vaccines as an effective means to contend with infectious disease, which to varying degrees reiterated the vaccine narrative (see Heller, 2008: 13). Even so, interviewees explained the limitations of their personal knowledge and thereby, evidenced some of the ways that health professionals manage medical uncertainties.

## **Medical uncertainty**

Interviewees' certainty regarding the necessity of vaccines accompanied evidence that most health professionals I interviewed (excluding Public Health nurses) were at minimum uncertain about some scientific details about vaccines. These uncertain details are unsurprising, given the

<sup>40</sup> As I mentioned in the introduction, I discuss contradictions and counter narratives in the following chapter—such as arguments that flu vaccines were ineffective, or specific vaccines carried greater risk of side effects than others.

nature of medical knowledge and health professions. Angst and uncertainty are traits of the health professions, regardless of one's awareness of them (see Gerrity, Green, and Bendelow, 1992; Griffiths et al., 2006; Fox, 2012; Knight and Mattick, 2006; Schattner, 2009). Health professionals, who apply medical science to diverse bodies, practice with personal knowledge that is specific to their specialty. Even health practices with supposedly determined outcomes involve minimal uncertainty and involve some degree of trust in medical science, its creation of specific treatments, and their application to individual bodies in miscellaneous contexts (Knight and Mattick, 2006). For example, Lynn Valerie Knight and Karen Mattick (2006) explained that medical students learn that uncertainty is a central component of their practice: "The development from lay conceptions of knowledge, where science is considered to be a place of certainty and 'truths,' to an understanding of knowledge as being more contextual, contingent and fluid is an important transition for effective medical practice" (p. 1085). Even without doubt in the best course of action, some uncertainty is inherent to medical practices.

Renée Fox (1957) suggested three broad categories, which include the gaps in individuals' knowledge, the limitations of the medical field, and the difficulty distinguishing between the two. Fox (2002) divided her categories of uncertainty as two broad categories with various subcategories. First, intellectual or scientific uncertainties comprised such issues as: 1) the impossibility anyone could master all of medicine's knowledge and skills; 2) the difficulties distinguishing personal ignorance from ineptitude; 3) the gaps and limitations inherent to medical knowledge and effectiveness; 4) difficulties recognizing gaps in personal knowledge and medical knowledge; and 5) the confines and inabilities of the medical practice; and 6) the ongoing changes and updates to medical knowledge (p. 237-238). Intellectual and scientific uncertainties seem to split between uncertainties that were internal to the professional (i.e.,

mastering skills or recognizing one's own ignorance), and those that fit within the broader professions of medical knowledge (i.e., gaps, limitations, and the incapabilities of medicine). Second, Fox (2002) identified existential uncertainties, which include major cultural and ethical concerns pertaining to medicine: any uncertainties that arise with human illness and associated human suffering, life, and death; and the meanings of suffering, life, and death (p. 238). During my interviews with health professionals, existential uncertainties arose regarding ethical dilemmas, policy concerns, and concerns about the spread of disease. Some interviewees touched upon such ethical uncertainties as responsibility to the population and parental rights when discussing vaccine policy. Nonetheless, interviews focused primarily on intellectual and scientific uncertainties.

Paul Atkinson (1984) heavily critiqued Fox's interpretation of her data. He questioned the purpose of lumping various forms of uncertainty into a conglomeration that made uncertainty appear to be a pervasive presence in medical practices (p. 951). Atkinson (1984) argued instead that medical education involves "training for certainty" that frees them from experiencing doubts in their actions (p. 952). Atkinson (1984) cautioned about the temptation of the view that: "medical knowledge and practice are inherently 'uncertain,' while the 'certainty' of dogmatism and personal judgment are responses to that on the part of the clinician" (p. 954). He explained instead the need to address "certainty" and "uncertainty" as equally relevant to interpreting medical discourse. Some recent research, however, explained that uncertainty (or otherwise subjective knowledge) is increasingly recognized as a component of medical practice (Knight and Mattick, 2006; Schattner, 2009). I rely on the word *uncertainty* to describe what health professionals told me was beyond their own knowledge regardless of whether that uncertainty generates *doubt*. That is, my use of the word uncertainty does not imply an immobilizing force or

even a contradiction to the vaccine narrative or medical discourse. It is simply what falls beyond the known, an issue that many health professionals leave unaddressed regarding vaccines. Conversely, *doubt* is an experience that can accompany uncertainty, which involves difficulty deciphering the best course of action. Indeed, in this chapter I focus only on uncertainties that leave the grand vaccine narrative intact. In the following chapter, I address how some of those uncertainties can manifest doubt.

I leave Fox's (2002) existential uncertainties beyond the scope of this chapter, aside from a brief comment here. In some instances, interviewees mentioned complications such as time constraints and offending patients who oppose immunization as issues that factored into their counselling. That is, they mentioned uncertainties that included ethical dilemmas and other complications that can create angst. Such angsts can include: fears about litigation or patients' complaints, healthcare organizations' demands that can contradict patients' needs, time constraints that restrain each patient encounter, concerns about intimacy and emotional patient encounters, patient demands for specific procedures and information, and the increasing and potentially distracting role of computers in the clinic. Finally, health professionals may experience work-related distress, which can inhibit their abilities to manage other issues (Schattner, 2009: 76-77). In addition, social influences on knowledge and uncertainty impact the recommendations that health professionals provide patients and their families (Bazylevych, 2011; Blume and Zanders, 2006: 1833; Chen, 2005: 39; Gerrity et al., 1992; Skea et al., 2008). As such, the uncertainties most prevalent to this study included professionals' personal uncertainties, the uncertainties inherent in the medical discipline, and uncertainties that manifest through human interactions (such as those involving patient records and the impact of counselling).

# The professional's personal uncertainties

Health professionals cannot know the entirety of medical knowledge and so they trust some details to experts in each specialty. The nuances of each vaccine are beyond most health professionals' and even some vaccine experts' knowledge base. Lindsay Prior (2003) explained that medical doctors are experts only in their area of specialization. With vaccines, most uncertainties that stem from personal knowledge involve limited concern for safety because they are based within trust and experience that certain medical procedures are necessary to secure health.

Interviewees alluded to some of their uncertainties, then often provided some type of evidence supporting vaccine necessity. <sup>42</sup> For example, Ren, who is an urban family physician, shared a family narrative about children dying from vaccine-preventable diseases:

Ren: Yeah I think once they make that decision [not to vaccinate] they stick with what's going on with that. And really, it's not a very intelligent decision, because four generations ago, my grandmother had acceptable losses in my extended family of four out of sixteen children before school age died of infectious diseases that kids get prevaccination. That was acceptable losses. And she said you don't have much time to linger by the grave because she had a busy household. She had twelve other kids to raise and take care of in a rural situation where they had to do other stuff [...] So, I mean I think a lot of our patients don't get what the real world is like without vaccinations. And I think a lot of the naysayers right now are depending on all those who do get vaccinations to protect their families. And they are part of that [un]vaccinated pool and once we get below 80% vaccination--now we've got risk of sub-epidemics going on.

who voiced strong opinions against vaccines.

<sup>&</sup>lt;sup>41</sup> As such, some vaccine research conducted by medical doctors who specialized in other areas created the appearance of legitimate evidence without generating reliable information (Prior, 2003: 51). Here, I refer back to Andrew Wakefield and his colleagues' (1998) study that erroneously linked autism and the MMR vaccine and the numerous other health professionals

<sup>&</sup>lt;sup>42</sup> As I explain in Chapter Six, these forms of evidence are telling in that health professionals present personal stories as evidence, whereas they present patient stories as misinformation.

TM: Do you think it's below 80% for all vaccinations that causes that? [...]

Ren: I don't know. I don't know the details, yeah. That's why we have immunologists. Ren's uncertainties and his story exemplified some issues that emerged during interviews. First, he asserted knowledge of the risk of disease and the ability of vaccines to prevent disease. Second, he evidenced some personal knowledge gaps—specifically, he is uncertain as to the uptake level required to maintain herd immunity (even though he stated a percentage before admitting his uncertainty). Third, he reproduced a common conception that vaccine refusers would comply in the future if herd immunity failed and epidemics re-emerged on a grander scale than they already have (i.e. the "real world" motivates vaccine compliance). Fourth, Ren used a family narrative as evidence rather than relying upon statistics or clinical information, which implies that he recognized the weight of a personal story in swaying vaccine opinions. Finally—and most importantly for this chapter—he stated his uncertainty regarding the needed uptake rate for herd immunity as something that he trusted to experts (immunologists). Therefore, he framed uptake rates as beyond his knowledge and scope of practice, but addressed within medical knowledge.

## *Uncertainties inherent to the health professions*

With any knowledge, and especially with knowledge involving diverse biological bodies, what can be known oversees increasingly vast expanses of obscurity (Knight and Mattick, 2006: 1085). The ongoing expansion of knowledge generates new uncertainties (Gerrity et al., 2003): "Contrary to all expectations, the spectacular advances in our knowledge and capabilities have not reduced uncertainty regarding the individual patient. The practice of medicine is not only becoming increasingly complex, but paradoxically, even more uncertain" (Schattner, 2009: 76). As such, any healthcare initiative has the potential for unforeseen and even indirect side effects. Said otherwise, advancing medical knowledge creates a "risk of risk" (Fox, 1988: 548).

Uncertainty is innate to the application of medical knowledge, which is gathered from scientific laboratories and clinical trials, then applied to the individual bodies that comprise the population (Griffiths, Green, and Bendelow, 2005; Knight and Mattick, 2006: 1085). The nature of clinical trials and statistical research generates uncertainty because one only can know statistically predicted outcomes from each procedure.

This uncertainty, although slight, exists with the application of vaccine research to individual patients. Maryna Bazylevych (2011) researched Ukrainian physicians' uncertainty regarding immunization and government policies. She interviewed Ukrainian health professionals to find that some of them bent official immunization policies in order to rely on their own expertise and opinions when providing vaccines to immunocompromised children in a country that mandates 100% uptake regardless of the condition of individual patient bodies (Bazylevych, 2011: 438, 444-451). In relation to Bazylevych's (2011) findings, the minute risks associated with vaccination, including specific vaccines and vaccine components, may be difficult for many to grasp.

This uncertainty about vaccine risks could be especially true, given that some of the scares that emerge regarding vaccines remain investigated due to the cost of research (both from financial expenses and from delaying a vaccine programs). Some agencies easily could spend all their time investigating risks without finding conclusions or doing anything else (Sunstein, 2002: 142). Even so, public reactions to research about risk can motivate regulation beyond what scientific evidence demonstrated was the safest. For instance, Cass Sunstein (2002) critiqued regulations to remove all arsenic from drinking water. He stated arsenic could be far less harmful in extremely diluted concentrations than regulation would suggest. He suggested the possibility of minute benefits from extremely small doses of the toxin: "animal studies even suggest that

arsenic may be a nutritional requirement, though there is insufficient data to indicate any nutritional role in human health" (Sunstein, 2002: 162).<sup>43</sup> As such, the regulation of arsenic beyond its recognized toxic level could produce what Fox (1988) called a risk of risk.

For example, the health professionals I interviewed overwhelmingly stated support for all of the vaccines that are listed on the Alberta immunization schedule. 44 Yet, some expressed uncertainty about whether under exceedingly rare circumstances vaccines had harmed a child. When stating these uncertainties, they cautiously maintained that the benefits of (most) vaccines were immense and that the risk of harm was negligible. One urban paediatrician, Javen, shared a story about a family physician who suspected vaccines were responsible for his daughter's disability:

Javen: I met one family physician [whose] child had some kind of neurological thing [...]. And they ask, even the specialist--they thought that it could have had something to do with early vaccines and, well, she died eventually, [...] completely brain damaged, and, you know, they had to care for her up to six years. So [...], you see, those Family Med--understandably they've, you know, seen some of the bad sides.

TM: So that one, do you think that it could've been linked to the vaccine or you just don't know yourself?

Javen: It can have [...], but, yeah, you don't know. Metabolic, but it's rare, but it's there. It's definitely there easily, like if you get the disease naturally, then [...] I know with measles, then you have a bigger chance of getting the neurological thing.

Javen was careful to list the risks associated with the disease as greater than those with the vaccine, yet his explanation suggested that it was impossible to know whether the disability resulted from the vaccine or another cause.

## Patient histories and counselling

<sup>&</sup>lt;sup>43</sup> In 2000, the EPA identified "0" as the standard required for safety because they failed to identify a safe level (Sunstein, 2002: 162).

<sup>&</sup>lt;sup>44</sup> As I discuss in the following chapter, some interviewees were hesitant about specific vaccines.

In addition to navigating medical and personal uncertainties, health professionals often work with the incomplete and fragmented information that patients share with them. Lynn Valerie Knight and Karen Mattick (2006) found that medical residents learn to navigate uncertainty surrounding what patients share with them when applying population-based medical research to individual patients (pp. 1085, 1088). Interviewees expressed frustrations regarding their efforts to obtain adult patients' vaccine records. Zarah, who is an urban family physician, asked:

[...] who from forty years ago kept all their records? Most people don't have it. And if Public Health kept that, they should be able to tell you where you [...] should be able to look it up, or find out where they were done and then tell you where you can verify these things.

Nisa, who is another family physician, expressed similar sentiments:

Well, I ask them, but you can't trust—I mean first of all, you know they don't know what Tdap is, and they might know I had measles, but if I say, 'did you have Tdap?,' they say, 'well, what's that?'<sup>45</sup> But if I ask if they have pertussis [vaccine], they may say, 'yes I had pertussis, but I don't know if I had tetanus with it--I don't know.'

Similarly, nurses who worked outside Public Health expressed frustration at their attempts to gather patients' vaccine information. Access to accurate adult patients' records was a point that several interviewees sought to drive home. They argued that without knowing patients' records they could not ensure adults' herd immunity despite the availability of booster vaccines in Alberta.

Some interviewees further explained that they were unaware of Alberta's vaccine guidelines, provincial immunity levels (which vary per vaccine), or whether their counseling was effective.

A family physician, Monica, explained that the effect of her counseling efforts was unknown:

"So it'd be interesting to see, I would want to be able to know whether or not it does make a

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<sup>&</sup>lt;sup>45</sup> Tdap is the vaccine that offers immunity to tetanus, diphtheria, and pertussis.

difference because, yeah, I have no idea. It seems to at the time." Monica appeared optimistic about her counselling, but some health professionals expressed that they felt speaking to patients who strongly opposed vaccines wasted time and energy. The outcomes of their attempts to counsel patients was unknown, and so they interpreted each encounter based on their experiences counselling for other treatments for which they could observe the outcomes (e.g., attempting to convince diabetic patients to follow healthier diets). They explained that they were even unsure if patients followed their referrals to other health professionals (i.e., a Public Health clinic, travel clinic, or pharmacy) to receive information or a vaccine. 46

## **Practicing with uncertainty**

Medical uncertainty and the means through which health professionals navigate it, have received increasing recognition from medical practitioners and researchers (see Eborall and Will, 2011; Knight and Mattick, 2006; Lingard et al., 2003). The uncertainties I discuss in this chapter failed to impact health professionals' intentions to recommend vaccines and fell short of contradicting the vaccine narrative. These uncertainties were dismissed as unimportant or subdued with various tactics that confirmed the most desirable course of action. Many health professionals constructed certainty with the vaccine narrative even if they carried uncertainties regarding specific vaccines. For instance, some health professionals (such as Anita, Javen, and Ren whom I mention above) explained that the benefits of vaccines were so immense that the risks were irrelevant during decision making. Health professionals often referred to authoritative knowledge from medicine, government policies, or their trust in the progress of medical science

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<sup>&</sup>lt;sup>46</sup> Stuart Blume (2006) found that parents depicted physicians to be uninvolved in providing detailed vaccine information, and therefore, an obstacle to gathering information (p. 637). Because I have investigated health professionals' perspectives, I did not measure how effectively they provide patients with information. Nonetheless, some shared explanations and emotional responses to vaccines that would suggest great involvement.

to bolster their certainty. Others explained that they were certain that informed consent was more important than pushing vaccine uptake onto those who were opposed. That said, at times these health professionals doubted whether vaccine refusers made informed decisions about immunization and frequently used *informed* to specify knowledge of medical science. Each of the efforts to practice with uncertainty that I detail below differed somewhat, but all of them maintained the grand vaccine narrative.

#### The vaccine narrative

Jacob Heller (2008) wrote *The Vaccine Narrative* to explain how vaccines are a cultural (rather than exclusively medical or scientific) phenomenon, which has important meanings in American society. 47 Like all narratives, the vaccine narrative, depicts a sequence of events, which results in specific outcomes (Heller, 2008: 9). In this narrative, vaccines are a technology wielded by the scientific community to protect the populace:

The cultural narrative of vaccines tells the story of a deadly disease that exerts a terrible toll in human suffering and death. Heroic researchers, working altruistically, marshal the forces of modern science to develop a simple intervention to ready the body's own defenses: a vaccine. Properly prepared, we can defend ourselves, just as our science demonstrates human mastery of death (Heller, 2008: 22).

Recognizing this description of vaccines as a narrative, one can question whether events unfolded in such a way to fit with the common conventions of a story. Contradictions to this narrative are absent from its simplistic rendition of events (Heller, 2008: 7). Nonetheless, "The vaccine narrative, like all stories, contains a moral: vaccines are the best and only way to contend with infectious disease" (Heller, 2008: 13). Any supporter of health would support the

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<sup>&</sup>lt;sup>47</sup> Likewise, Andrea Kitta (2012) wrote about the vernacular beliefs and practices surrounding individual Canadian's vaccine decisions. While Kitta (2012) primarily discussed the roles of rumours, legends, and other narratives in the perception of risk, her book offers insights into the multiplicity of small vaccine narratives.

widespread use of such a treatment. Although many interviewees mentioned uncertainties and possible risks involving vaccination, these contradictions failed to damage the overarching moral of the vaccine narrative.

# The vaccine narrative in policy

This grand narrative exists within historical accounts, popular understandings, and government policies. The first paragraph of the *Canadian Immunization Guide* contextualized the vaccine narrative as an ongoing story in which vaccines continue to rid the world of disease:

The goal of those concerned with immunization is the elimination of vaccine-preventable diseases. Eradication of smallpox has been achieved. Currently, global efforts are directed at the eradication of polio and the elimination of measles. Ongoing immunization programs with high vaccine coverage are needed to maintain low levels of other vaccine preventable diseases (PHAC, 2006a: 3).

In this excerpt, the eradication of diseases other than smallpox is depicted as a possibility pending vaccine uptake. As I mentioned in the Introduction, the *Alberta Immunization Strategy* (2007-2017) labels the immunization story one of "the greatest medical success stories in human history" (Alberta Health, 2007: 3). The guide then stated the need for ongoing immunization to overcome recent outbreaks that have occurred in Alberta and Canada. It framed itself as an authority that has responded to vaccine research and progress with successive updates and funding. Alberta's guide boasted: "Alberta has the most comprehensive immunization program in Canada" (Alberta Health, 2007: 3). As such, Alberta Health and Wellness characterized itself within the vaccine narrative as vaccine hero and an authoritative information source.

## The vaccine narrative in interviews

Similarly, interviewees relied partly upon the grand vaccine narrative to dismiss vaccine uncertainties. They stated with certainty that most routine childhood vaccines were necessary and controversial to patients only. For example, I began this chapter with Kian's assertion that

vaccines are necessary: "[...] I think that in the present age, you must vaccinate your children."

Nonetheless, the recognition of the vaccine narrative allows one to see how narrative can hide contradictions to the story's moral, such as Kian's statement that he had vaccine "cautions." One paediatrician explained her practice was more ambiguous than the vaccine narrative, which she learned in medical school:

I think that [...] when I was in medical training and residency the way in which the curriculum is delivered around immunizations is sort of [...] these used to be a worldwide problem, now these vaccines have been developed, everyone gets them, isn't life grand. I think in clinical practice, and the clinical research, and the colleagues, and the healthcare settings that I've worked in—I don't think it's quite that straightforward. I think in particular, there're misgivings (Chandra, urban family physician).

Chandra explained her misgivings, but emphasized her recommendations that parents follow Alberta's vaccine guidelines and that she and her children were fully immunized. Her belief supported the vaccine narrative, which she complicated with lesser uncertainties.

Expectedly, interviewees reproduced the vaccine narrative through assertions that vaccines save lives, especially children's lives, and refusals produce risk. For instance, urban family physician Aalia reiterated the vaccine narrative when she shared a story about the disappearance of diseases, which she attributed to the development of vaccines schedules:

I think it's just such an important part of our healthcare. It's revolutionized, you know, infectious diseases. I had a visiting doctor from Pakistan a few weeks ago. And, you know, there they really don't have the same types of immunizations [...] She said there, as a family doctor, most of her time is spent on infectious diseases. And here it's just so different. I mean, I focus more on screening and preventative care, that sort of stuff. And I think that, I mean, don't get me wrong, there are other new emerging things, you know, problems in our health as a population, which are no better, no worse that the infectious diseases we prevent with immunizations. But, I think that people don't always think or

realize the huge wide impact that vaccines have. You know, the number of theoretical lives that have been saved.

Narrations like these reiterated the spread of diseases throughout the population, until medical progress resulted in vaccines that created herd immunity, and then diseases receded into distant memories. These narrations omitted doubts in vaccines, and created medical certainty.

Consequently, I believe that the vaccine narrative was partly ground in illusions of medical

# The production of certainty

Gerd Gigerenzer (2003) argued that health professionals create an *illusion of certainty* when facing the unknown. This illusion of certainty offers several simplifications: "such as that treatments have only benefits but not any harm; that there is one and only one best treatment; that a diagnostic test is absolutely certain" (Gigerenzer, 2003: 21). As such, health professionals often speak and practice with certainty that particular treatments produce precise and limited outcomes. Likewise, Rayna Rapp (1999) described the suppression of uncertainties in her study of amniocentesis:

Among insiders, the acknowledgement of ambiguity, uncertainty, and stabilizing judgment calls is part of normal and normalizing cytogenetic practice. So, too, is its containment through limiting the recognition of its potential impact: When questions are raised about the status of a scientific fact, they need to be resolved by expert agreement for routinized diagnoses to proceed (Rapp, 1999: 209).

Rapp (1999) described both uncertainty, and its suppression—that is, health professionals are aware of their uncertainties, yet they practice as though they have certainty.

"The benefits outweigh the risks"

Certainty in the security of the population

certainty and conceptions of progress.

The vaccine narrative addresses both the population through public health and public policy, and the individual through medical care (Heller, 2008: 11). It asks the population to accept vaccination for the greater good and to protect those who may be at greater risk, rather than prioritize *only* one's own health—I italicize only to emphasize that healthcare professionals often argued that vaccines also protected the individual (Heller, 2008: 11). This narrative, therefore, characterizes the population as something to which one has responsibility to protect through individual efforts to control the circulation of disease.

Some health professionals considered individual patients in relation to the maintenance of population health, even with extremely rare risks to individual patients. Ren, who is an urban family physician, explained that he was "confident in the whole concept and process of vaccination delivery" for the population, then elaborated that, "I'm confident that by the time it's gone to market it's passed a certain process criteria have embedded in the least of me at point of care I shouldn't have to worry about that stuff." Yet, he detailed his experience treating a boy who became disabled following a measles vaccination:

Yes, if we get a big reaction to a vaccination with a raging fever that is out of control and/or rashes or airway difficulties we would stand down for the future for obvious reasons. I have one patient in my practice who is a group home patient he's a dependent adult. He developed an encephalopathy<sup>48</sup> after a measles vaccination as a child and that was the cause of his permanent disabling brain injury. It's real, it can happen. And that person got hurt and maimed for life to save other lives. So for my individual it's a disaster, for the rest of the population it's a measure of healthcare. For my guy, you know, it's a disaster for him (Ren).

<sup>&</sup>lt;sup>48</sup> Encephalopathy refers to brain dysfunction, which is "marked by varying degrees of impairment of speech, cognition, orientation, and arousal" (Venes and Taber, 2009: "encephalopathy").

Ren explained that on a one-off disability from vaccine remained a small possibility. But, he explained vaccinating is worthwhile: "The statistics say that it is right" Then he compared vaccine risks to his family narrative (which he repeated throughout the interview) about his grandmother losing four children, "Four healthy kids gone before school-age because no vaccinations from childhood diseases that are preventable now." Despite potential "disaster," Ren stated that vaccines save lives through both statistical evidence and a family narrative. Then, Ren listed his perception of common minor side effects and vaccine related risks:

Fever's typical and we just train all our patients to manage it and to call us if they can't manage it. So, and usually by three days, it's gone and I haven't, in the last decade, seen any major reactions from vaccination (Ren).

Likewise, most health professionals expressed limited concern for most risks associated with vaccines. They conceptualized risks primarily as limitations in vaccine efficacy and short term expected side effects (e.g., fever, sore arm, rash).

# Certainty of benefits

Medical treatments are somewhat illusive in that we can only be reasonably certain of their benefits. Benefits always accompany some costs and uncertainty. With vaccines, it is uncertain whether each vaccination that is applied to each individual body will produce safety and immunity, even if the likelihood of desirable (or at least harmless) outcomes is exceedingly high. During interviews, I found that expressions of certainty tended towards desired actions (i.e., one is certain that humans need to be vaccinated). Healthcare professionals' understanding that vaccines are necessary is based on beliefs that refusing vaccines creates risk, and that most vaccine risks are too minute to justify vaccine refusal. Rather than only medical discourse, however, they expressed this certainty through narratives, informational statements, and emotional reflections. In fact, many interviewees explained that they had complete confidence in

the benefits of what they described to be a superficial understanding of the medical science backing vaccines.

Interviewees made statements about ability of vaccines to secure health, despite minor gaps in their personal knowledge. When interviewees reduced vaccine risks to negligible, they produced similar arguments to cost-benefit analysis, which can inform governmental policies:

Cost-benefit analysis can often produce an illusion of certainty. Even where [...] science has a great deal to offer, the most that the agency can be expected to do may be to specify a range, sometimes a wide range, without assigning probabilities to various 'points' along a spectrum (Sunstein, 2002: 154).

For example, vaccine manufacturers have changed vaccines in response to public alarm about vaccine side effects, adjuvants, and preservatives beyond what scientific testing would suggest.<sup>49</sup> Sunstein (2002) argued that safety is a spectrum, which lacks definitive certainty of a procedural outcome (similar to Gigerenzer's research about the illusion of certainty). In fact, interviewees reiterated various phrasings of nurse Shannon MacDonald's statement to the CBC: "These diseases are the thing to be afraid of and the vaccines are just by and far the safest option" (Griffith-Greene 2014: para 43). Sunstein (2002) explained, "safest" implies the least known risks with the best-known outcomes, but that even with simple initiatives risk-free remains impossible.

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<sup>&</sup>lt;sup>49</sup> Many of the controversial components in vaccines have been removed from vaccines, but the risks associated with these components appear to be imaginary or theoretical. Yet, the removal of these components could improve safety through increasing vaccine uptake and thereby, herd immunity. In the absence of confounding factors, such as a disease outbreak, more parents comply with vaccine schedules when vaccines are free of specific adjuvants, such as thimerosal (a form of mercury), which sound scary despite the lack of research to indicate danger (Mnookin, 2011: 6). As such, public opinion impacts vaccination policies because many humans are noncompliant with regulations that popular discourses label unsafe (Chen, 2005: 49; Phipps, et al., 2011: 286).

When clarifying, that vaccines rested on the safest end of this spectrum, most healthcare professionals reworded and elaborated on the simplistic statement that many vaccine critics claim dominate vaccine counselling (i.e., "the benefits outweigh the risks"). For example, Nisa, and urban family physician stated: "[...] I think there are limitations in the efficacy, but I don't really worry about, I mean that's the best we have." Similarly, rarely, did substantial risks factor into interviewees' representations of vaccines. Tori, a Public Health RN, explained:

I'm a pretty fearless vaccinator. I never really had a problem with that. [...] We're not doing anything radical or, you know, I feel very confident in our vaccinations. I mean I know that there have been tragic errors in the past, but you know [...] the benefit outweighs the risk (Tori).

Indeed, all interviewees explained that the refusal of some, if not all vaccines was dangerous and some provided narratives to exemplify their claims.

For instance, Taran, who is a pediatrician, shared a story about a young patient who became severely ill from H1N1 influenza after his family missed his flu vaccine:

But the one kid who had asthma and was very well controlled on medicines, but then got H1N1, and got too sick, and too sick to the point that this child had to go to ICU. And after ICU he was in incubator and then afterwards on ventilator and then he has to go on ECMO.<sup>50</sup> (TM: ECMO?) Yeah, ECMO is a [...] machine. [...] The survival rate is very, very low after that. [...] So I had what was kind of very, very tough on the medical faculty that you what this is a healthy child who came in was playful was active and suddenly got so sick that he has to go on ventilation and then on ECMO. Luckily he came out well. He survived and I saw him in a follow-up clinic and was very happy to see him again walking and though he has some weakness in his arms now. I was very happy to see him in my office again and chat with him. So, I was asking family who was, "Oh we

syndrome, pneumonia, or persistent pulmonary hypertension (Venes and Taber, 2009).

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<sup>&</sup>lt;sup>50</sup> ECMO stands for extracorporeal membrane oxygenator. It is "An external device that oxygenates blood delivered to it from the body and then returns it to the patient" (Venes and Taber, 2009). ECMO is used experimentally on patients with acute respiratory failure and on newborns who have failed to respond to the standard treatments for meconium aspiration

gave it last year, this year we [missed it]." So, things do happen. So, that is my example of things that, you know what, I should of [...] advocated more (Taran).

Taran's story framed the flu vaccine as essential to the prevention of severe illness and death with limited safety risks. Yet, he admitted, "[...] with everything the efficacy is not a hundred percent." Many interviewees elaborated that their perception of risks was exceedingly minimal. Even Ren and Javen (whose narratives I shared above about children becoming disabled) explained the unlikeliness of such risks.

## Emotional investment

Each interview opened with me asking: "what was Alberta's biggest vaccine related issue?" In response, almost every healthcare professional stated some form of patient uncertainty, vaccine uptake, or vaccine refusal. Responses to this question often involved emotional investment, which I took as an evidence of the depth of the belief in the necessity of vaccines. For instance, when I asked Milan, a rural family physician, about the biggest issue regarding vaccines in Alberta, he stated that certain types of vaccine refusals "bug" him more than others.

The biggest issue is I think are parents refusing to vaccinate their children for whatever reasons. I guess the ones that bug me the most are the ones that feel they're informed and it's not for religious reasons it's just because they think that doctors are trying to poison their children. So, especially since it seems to be a problem because there's been less parents vaccinating their kids and we seem to get these little outbreaks of childhood illnesses that should be well controlled with vaccines (Milan).

Olivia, an RN in a family physician practice, detailed similar frustrations at length, and stated an exceptional confidence in medical science and objectivity:

I kind of want to choke the person that came over from Holland, or whatever it was, and brought this [measles outbreak] here. It's infuriating. It's just infuriating that we're so close. So close to eradicating so many of these childhood diseases and the ignorance of people is bringing them back. [...] Infuriating is the best word I can use to describe it.

And [...] when I hear stories of children that couldn't be vaccinated because of something and then they get sick, I feel so helpless. And you know, like I was kind of joking before, but I'm serious. On Facebook I do, and I really try to I have my comments, like, intellectual, like, sure I'm mad, but I don't go like, 'you stupid, fucking—' Like I don't go off like that. But, it's the scientific method, [...] this is how we remove emotion from it, we find out scientifically that, you know, the benefits outweigh the risks. And, I try to like get this into people's heads that intellectually this—But yeah, it's coming up more often with obviously, this measles thing and with the flu outbreak this last [...] time—Yeah, just sometimes feel like I'm yelling to a wall and nobody's listening. (Olivia).

Olivia's claim that science removes emotion from vaccine research contrasts her expression of anger. Nonetheless, it is understandable. She believes that parents are endangering children by refusing vaccines, which scientific facts support. Even those who expressed less certainty in scientific knowledge expressed similar frustrations with vaccine refusals, to which they often attributed Alberta's recent outbreaks of measles and pertussis.

## Trust in progress and authoritative knowledge

Trust in authoritative knowledge is based in the premise that expertise creates the most accurate interpretations of a phenomenon. Many social scientists have dismissed the view that experts have access to the truth (Collins and Evans, 2002). Nevertheless, Collins and Evans (2002) argued that expertise needs to maintain its authority: "we have to treat expertise in the same way truth was once treated — as something more than the judgement of history, or the outcome of the play of competing attributions" (Collins and Evans, 2002: 237). Yet, they also explained that it may be necessary for research to include "experienced-based experts" during the research process (Collins and Evans, 2002: 239). They explained that experience-based

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<sup>&</sup>lt;sup>51</sup> Their example demonstrated how the Cumbrian sheep farmers in Brian Wynne's research could inform radiation scientists about their experiences farming in regions affected by the

experts could share contributory experts because, in some respects, their expertise can offer new perspectives to the scientists directly involved in research that backs policies (Collins and Evans, 2002: 255). Most interviewees deferred to expert or authoritative knowledge when explaining their trust in vaccines without directly citing their knowledge and the experience-based expertise they had from their own professional practice. With vaccines, parents could have similar experience-based expertise that may be relevant to some vaccine issues, but an over reliance upon experience can result in such questionable research and Wakefield's fraudulent investigation of the MMR vaccine and autism.

The health professionals whom I interviewed who worked outside of Public Health often explained that they could trust Public Health nurses and other professionals to address vaccination. They often shared the story that science had progressed to the point where vaccines offer a mastery over disease and death, which aligns with both the vaccine narrative and the myth of progress. Then, several interviewees described their expectations for progress to continue.

# Progress and paradigms

As a profession, medicine maintains its dominance over jurisdictions relating to health through the maintenance of scientific knowledge (see Abbott, 1988: 55). In principle, a profession's abstract knowledge can be assembled into full and fully rational system (Abbott, 1988: 55). This ideal, however, only exists in textbooks (Abbott, 1988: 56; Kuhn, 1962). Medical knowledge is based in scientific knowledge, which always involves some uncertainty. Thomas Kuhn (1962) explained that normal science is practiced as though the current paradigm is

radioactive fallout from the Chernobyl disaster (Collins and Evans, 2002). Specifically, they explained that even without scientific expertise, sheep farmers knew about the ecology and behaviour of sheep, and of rain water (Collins and Evans, 2002: 255).

flawless and the history of scientific revolutions is hidden. He elaborated that after a scientific revolution, which involves replacing an older paradigm with a new one, textbooks are rewritten as though older scientific knowledge transitioned directly toward the new paradigm. Rewritten textbooks misrepresent scientific developments as a linear progression towards truth with few errors, which represents the knowledge within existing paradigms as infallible (Kuhn, 1962: 137). That is, the knowledge within textbooks appears as something that is certain and built through adding rather than through changes. As such, uncertainties are likely to remain within any paradigm:

Paradigms gain their status because they are more successful than their competitors in solving a few problems that the large group of practitioners has come to recognize as acute. To be more successful is not, however, to be either completely successful with a single problem or notably successful with any large number (Kuhn, 1962: 24).

That is, a dominant scientific paradigm inevitably fails to explain every question within a scientific field. The role of uncertainty in medical science is similar in some ways. Of course, medical practice differs from scientific knowledge. Yet, textbooks address the history of medicine as if it transforms quickly with scientific ingenuity, rather than seeping slowly into medical practice amongst health professionals who are wholly committed to older treatment options (Wootton, 2006: 17).

In relation to the myth of progress, interviewees supported the vaccine narrative by stating that vaccines continue to improve. When I asked if vaccines had become safer over time, one rural Public Health nurse detailed the continued improvements in vaccine safety:

MaKenna: I think they're way more safe. They're researching them all the time. You know in the past there was, not problems, but probably more side effects with some of the vaccines, just because they were newer, and anyway they refined them and oh boy, it's just so much better. And the amount of antigens that used to be in vaccines versus what's

in them now is just so decreased; it's fantastic. I think they're just getting better and better and safer and safer.

TM: Do you think it's still improving quickly, or do you think it just kind of had a surge and then slowed down?

MaKenna: [...] I think it slowed down with some of our older vaccines because they're just so safe now, I don't know how they could get it more safe. The nice thing is they're combining more vaccines now into one needle, which is fantastic. Way less amount of shots and yeah, [...] I'm really happy with how they refined things and the low amount of side effects with them is really good.

Likewise, Olivia contextualized this progress within what she perceived to be widespread progress in product safety:

Yeah I think, just kind of with everything you know as we gain more knowledge about. Like cars are safer now than they were before you know just like that we're always looking to improve the safety of everything we provide to the public (Olivia).

Both nurses stated that progress occurred in vaccine safety, and should continue.

Many interviewees spoke as though progress towards vaccine safety was very near completion and continuing progress would involve newer vaccines.

Milan: I think it's excellent. You know there's always new vaccines coming around and it all seems to take a while to get a vaccine, like a good one right now that I don't think has coverage yet is the rotavirus vaccine, Rotavec, I've been recommending it to my patients and I think they have to pay a little bit for it.

TM: So [...] if you were to change things, probably what you'd want is more coverage? Milan: Well yeah and I understand that it takes a while to build up a certain body of evidence saying that it's safe and effective and worthwhile.

This progression specifically places vaccines in the immunization guide within medical certainty.

That is, such comments imply that following proper research vaccines deemed safe and effective become integrated into the Public Health Agency of Canada's recommendations and Alberta Health's vaccine schedule. This result also progresses conceptions of normalization. To be

normal is to be immunized; with progress normal bodies are immunized with more vaccines. Moreover, this progressive incorporation tells the vaccine narrative as an unfinished story of ongoing success. The climax of the narrative was the eradication of smallpox, but science continues granting mastery over more diseases.

Most healthcare professionals modelled their own story of learning about vaccines to the narrative of progress. They explained that ongoing learning involves adding new vaccines to their existing knowledge base through a building process, as though adding bricks to the foundation of a house: "I would say yeah it [my knowledge] has been changed because [...] I have seen changes in the vaccine schedule: The duration, the number of vaccines and the time period at which it should be given, so definitely" (Maya). Learning, as Maya clarified, involved placing newly gathered information amidst already personally known facts. Rarely did interviewees share narratives about their own learning that involved a moment of enlightenment or coming to accept a vaccine they had previously questioned. Such stories about learning referred only to the flu vaccine.

Some older healthcare professionals explained that their awareness of vaccine safety progressed with recent vaccine developments. As such, they told me how progress overtook uncertainty. For example, Javen explained that the acellular pertussis (whooping cough) vaccine involves fewer side effects than prior whole-cell versions. Nonetheless, Javen asserted that prior to the acellular vaccine, he recommended the whole-cell vaccine because of risk of pertussis-related death without it.

Interestingly, some interviewees reflected on changes to vaccines that improved public perception of risk as improving vaccine uptake, herd immunity, and therefore, population safety. As a rural Public Health nurse explained:

Lots of changes in vaccine safety, you know, parents complain about preservatives, they take them out. Our vaccines are safe with preservatives, but if that's what you want to see, they take them out. So then we're wasting more vaccines, they're not living on the shelf longer and things like that. So we do have a lot of waste there, [...] or some waste. But I think vaccine manufacturers listen to the public and they've changed immensely over the last thirty years. What a vaccine was [...] even when I was young, isn't what a vaccine was now (Amaya).

Amaya lamented that pharmaceutical companies designed vaccines to be safe through scientific progress, but also responded to public demands. When I inquired as to whether listening to the public in this way was beneficial, Amaya explained: "I think it is [...] because it builds confidence in people and maybe we have less hesitancy because of that, I'm not sure." That is, she suggested that allaying public fears about non-dangerous vaccine components increased safety because it increased vaccine uptake rates.

Even as a means to secure certainty in medical knowledge, progress remained a potential source of uncertainty: "If the lack of agreement among scientists were due to absence of knowledge, as information increases, disputes would decrease. On the other hand, better measurement opens more possibilities, more research brings more ignorance to the light of day" (Douglas and Wildavsky, 1982: 62-63). Regarding personal knowledge, several healthcare professionals (excluding Public Health nurses) elaborated that changes to the vaccine schedule complicated their efforts to remain up-to-date. Nisa maintained her trust in vaccine progress, while admitting to her personal knowledge gaps:

the preservative, [...] for example, they took away the mercury and really decreased the concentration. So, I think it's evidence-based, [...] I do rely on Public Health, [...] to make sure that you know the vaccines that I'm giving are safe, right? I mean, [...] they have access to a body of information and research, and so I don't keep as close track

because [...] I trust the organization. But, yeah, you hear things where they're changing (Nisa).

Nisa explained that she trusted Public Health to follow scientific progress because as a family physician, the details of vaccine updates were beyond her scope of practice. Even so, she explained that she would strongly encourage patients to receive their vaccines.

Trust in authoritative knowledge

Health professionals work in specific specialties, which necessitates their partial reliance on other sub-specialties. Lindsay Prior (2003) made a compelling argument that Andrew Wakefield relied on lay knowledge when he erroneously linked autism to the MMR vaccine in a scientific article (p. 51). Wakefield's study had immense influence on MMR uptake and an ongoing impact on public vaccine anxieties. Yet, Wakefield's credentials as a physician and his ability to publish a scientific article created what appeared to be legitimate evidence of risk (Prior, 2003: 52). Prior (2003) insisted that Wakefield had overstepped his professional boundaries and was equally qualified a "lay expert" in the field of his now retracted article. "Lay experts" may have valuable insight into their own experiences that experts can overlook, but basic dictionary definitions imply the term is an oxymoron—layman means not an expert (Collins and Evans, 2002: 238; Prior, 2003: 53).

Rather than over-extending expertise, many health professionals whom I interviewed explained that they either had extensive knowledge about vaccines (i.e., Public Health nurses and some physicians attended to extra vaccine courses or training), or that they recognized their scope of practice trusted respective professions. Although this trust represented a limitation of one's knowledge, it demonstrated an awareness of the impossibility to master the entirety of medical science. Without mastering all of medical science, trust in respective health professions is a means through which to avoid the immobilization that can accompany uncertainty. Yet trust,

even if only in minute details about vaccines, involves a "kind of suspension" rather than knowledge, which Hobson-West (2007) claimed involves bracketing off uncertainties (p. 200). Through this trust in medical science, health professionals can assume that the current treatment regime is the best possible option.

Recognizing their professional limitations, interviewees explained their reliance on Alberta immunization policies, other vaccine experts (especially Public Health nurses), and medical science. A nurse from a Family Medicine clinic explained:

Naomi: I think, so like, just being able to recognize that there's, you know, scientific papers that should be read and then there's things [...] on the internet [...] that don't have the credentials, but you know understanding the literature can sometimes be confusing for some people...

TM: Ok, do you ever find—

Naomi: I guess it just depends where you get the information from. Usually most of our information is sent to us from AHS [Alberta Health Services], in which case, I'm assuming that it's all correct.

This nurse exemplified her confidence by mentioning how Alberta Health Service's responded to vaccine risks appropriately:

I think that they do extensive research and if there is an issue with vaccines, then I think that they do their best to--like, for example, the influenza vaccine, it was recalled last year and I can't even remember why. But everything was pulled and we weren't giving vaccines and then they did the proper research and found that it was actually ok to give. So I think that's a good example that the efforts that they are taking [are] the right safety measures for, I think (Naomi).

Naomi's views aligned with most interview participants. Most interviewees extended their trust in medical science to a trust in policy—a trust that Alberta Health Services based the immunization schedule upon reliable data.

Physicians often cited Public Health policies and nurses as experts in vaccines, which they explained were beyond their practice. Ren explained:

So, the concept of immunization is my job. The detail of the best current regiment that has changed from a year ago and from a year before that is a job on my local health clinic, you know keep my kids [the children in his practice] up to date with that. [...] If they bring me an immunization record, I'll put it right into their EMR so I'm tracking with them so I know what they've had. But as far as initiating it or protocol or that sort of thing, no (Ren).

Ren carefully detailed the role vaccines played his professional family practice. He trusted medical science and other professions to maintain vaccine efficacy. This trust involved both a limitation of his practice, as well as a means to make decisions despite his awareness that some vaccine details were beyond his knowledge.

One urban family physician, Damian, shared a compelling story about trusting the knowledge vaccines that was based upon his personal experience:

[...] it's something that I don't really question, [...] so I haven't really put any effort into researching vaccines. I'm interested in travel vaccines, so I got some information into that. From my perspective, I have a hearing loss in both ears and I wear hearing aids and that's because I was born before [a specific childhood] vaccine became available. So I never had the [...] vaccine and I had [the disease] when I was 18 months old and have a consequent problem (Damian).

Damian shared his story about his experience with a now vaccine-preventable disease to legitimate his trust in the medical science and policies backing vaccines. Similar stories emerged in interviews of vaccine-preventable illness, death, and disabling side effects that interviewees, their families, and their patients experienced. With these stories, interviewees explained that vaccines were a basic health measure, which they trusted to secure health.

Olivia was particularly blatant about her trust in scientific medicine, the production of vaccines, and the policies behind them. When I asked if there was any scientific evidence that she would distrust, she answered:

There's none. I would receive any vaccine that would be recommended. The one that I know has the most side effects is yellow fever, but if I was going somewhere that yellow vaccine was recommended there's no doubt that I would get it. I have a lot of confidence in the system of checks and balances that exist. And I trust that there's people who know a lot more about this than me, and that's what their job is, and that's what they went to school and trained for. So why would I presume that I knew any more than they did, simple as that (Olivia).

When I ask if there were any moments that Olivia would hesitate to trust scientific results, she answered, "Nope." Unlike some of the healthcare professionals who voiced contradictions and gaps in their trust of specific vaccines, Olivia expressed complete trust.

#### Conclusion

I began this chapter with an excerpt from Kian and I return to his example as I discuss the importance of managing uncertainties. Kian's opening narrative about the need to vaccinate children and his "cautions" with vaccines reflect the vaccine narrative and the contradictions to it that exist. His statement, "you must vaccinate your children," reflects certainty in the necessity of vaccines regardless of specific uncertainties, or (as he stated) his "own cautions." As Kian had explained, "too big a dose" of his "own personal cautions" could result in turning against vaccines completely. Yet, Kian has managed his uncertainties such that he understood the necessity of vaccines. That is, through the various tactics I discussed in this chapter, Kian has overcome the potentially immobilizing features of uncertainty and formed a decisive professional opinion about vaccines that he can share with patients. Indeed, it appeared that Kian, like most interviewees, considered these uncertainties irrelevant when advising patients.

Kian was more open about his uncertainties than some health professionals with whom I spoke. Even so, those who claimed to lack cautions about the use of vaccines needed to manage the gaps in their personal knowledge.

I explained how health professionals whom I interviewed presented their certainty in the necessity of vaccines in relation to their uncertainties regarding specific details about vaccines. Interviewees managed their personal uncertainties, the limitations of medical knowledge, and their uncertainties about the information that patients provided. To do so, many dismissed their uncertainties through support of the vaccine narrative, which involved an illusion of medical certainty and/or trust in authoritative knowledge and progress. Interviewees all supported the vaccine narrative in varying ways, but they worked with the inevitable uncertainty that accompanies daily medical practice. Their narratives and explanations of vaccines demonstrated various tactics for working with mundane uncertainties in daily clinical practice.

Indeed, the management of such uncertainty is integral to effective patient care: "Both uncertainty and the doctors' inability to handle it may result in substandard care" (Schattner, 2009: 76). Variation in one's ability to manage uncertainty, even if only the uncertainty of minute details, could destabilize health professionals' roles promoting discourses about vaccine safety. While interviewees shared narratives with me that involved their personal experience with vaccine discourses, their experience demonstrate variation. This variation, I argue, could destabilize their roles promoting discourses about vaccine safety. Particularly, diverse views regarding vaccines mean that patients may engage with divergent perspectives from "experts" who are prescribed to be vaccine champions by the state (in this case such organizations as Alberta Health Services and the Public Health Agency of Canada). Yet, experience is a core feature in all professionals' accumulation of expertise (Collins and Evans, 2002: 260). While

most healthcare professionals whom I interviewed lacked specific expertise about vaccines, they demonstrated their expertise through their ability to interpret medical discourse beyond strictly regurgitating information found online or in any textbook. Moreover, the recognition of the limitations of their knowledge was a means through which they demonstrated their professionalism. Although only Public Health nurses claimed expertise specific to vaccines, all interviewees were experts in their area of healthcare. Even with mundane uncertainties, they expressed their ability to look into specific issues as needed and refer patients to colleagues if necessary.

Much sociology of health research has highlighted the "democratization of knowledge" (often as a desirable form of progress) and increasingly recognized role of uncertainty, which counter health professionals' legitimacy in their respective areas (Hobson-West, 2007: 211; Leach and Fairhead, 2007: 4; Lankshear, Ettorre, and Mason, 2005: 362; Prior, 2003: 43; Streefland, Chowdhury, and Ramos-Jimenez, 1999: 1712). This frantic desire to equalize all knowledge is problematic: "The romantic and reckless extension of expertise [to include lay experts] has many well-known dangers—the public can be wrong" (Collins and Evans, 2002: 271). Such a designation reduces health professionals' expertise to "just another opinion" (Kata, 2010: 1715). This designation ignores advances medicine has made in some of its attempts to save lives and the fact that in many instances, patients desire health professionals' advice when making health decisions (especially potentially life-determining decisions, such as cancer treatments [Sinding et al., 2010: 1097; Wootton, 2006]).

Research has increasingly recognized the role of uncertainty in medical practice, but most of it has focused on the bounds of knowledge with treatments that health professionals may doubt (Gerrity et al., 1992; Griffiths, Green, and Bendelow, 2005; Rapp, 1999). Health professionals'

uncertainties about vaccines in Alberta are unique in that they offer an opportunity to observe the uncertainties accompanying a widely accepted and long established medical treatment.

The grand vaccine narrative likely reflects many of the successes of that treatment (see Heller, 2008). The population, and thereby, most individuals within that population, appear to have avoided countless disease outbreaks through immunization. Nonetheless, this narrative often omits less frequently occurring counter narratives about vaccines causing the diseases they were meant to prevent, becoming carriers of a disease, or experiencing adverse side effects.

Overall, interviewees' general acceptance of the dominant narrative that *vaccines are safe and essential to health* (see Heller, 2008) seemed to incorporate the short counter-narratives—such as arguments that flu vaccines were ineffective, or that specific vaccines carried greater risk of side-effects than others.

## **Chapter Six**

# "I had to solve it for myself:" Accounts of the professional self and vaccine ambivalence Introduction

Canadian government guidelines about how to raise vaccine rates assume that health professionals support provincial and national immunization goals. Public discourses present health professions as though they hold unanimous views that are carefully constructed through regulatory bodies and standards for rigorous training (Abbott, 1988: 61). As such, patients' knowledge and education are scrutinized for such issues as decreasing vaccine uptake and the increasing prevalence of once invisible diseases. The attribution of these problems to patients' knowledge assumes that health professionals are knowledgeable, responsible, and capable of educating others. In practice, however, more diversity exists amongst health professionals than is readily acknowledged (Abbott, 1988: 65). Most of the health professionals whom I interviewed seemed to take their role advocating for vaccines for granted, but their accounts evidenced some diversity regarding their perceived roles in vaccine promotion.

Andrea Kitta (2012) explained such diversity as reflecting historical medical errors, which can weaken trust in medical knowledge. For example:

There have been many instances of vaccines which were thought to be safe proving to be deadly, especially in the case of killed vaccines,<sup>52</sup> and throughout the history of vaccination, there have been disasters in the manufacturing and distribution of vaccines (Kitta, 2012: 20).

"Vaccine").

<sup>&</sup>lt;sup>52</sup> By "killed vaccines" Kitta (2012) referred to vaccines in which the antigen has been disabled or "killed:" "Vaccines may be made from weakened or killed microorganisms" (Venes and Taber, 2009, "Vaccine"). Vaccines contain "molecules derived from a microorganism" that are intended to stimulate an immune response to a specific disease (Venes and Taber, 2009,

Following this statement, Kitta (2012) referenced the possibility that health problems—such as Sudden Infant Death Syndrome, allergies, autism, and other diseases and conditions—could be linked to the make-up or storage of the vaccine (p. 20). Despite the likelihood that vaccines directly caused most of these serious health problems, the ambiguity surrounding the origin of such conditions remains a potential source of vaccine ambivalence. For the general public, such ambiguity means that, "other reports of the information will fill the risk information vacuum" (Kitta, 2012: 117). Unlike the public, health professionals can appear to lack such an information vacuum because of assumptions that they hold unanimous views. For professionals who specialize in areas unrelated to vaccines, however, the mastery of such information is beyond their daily practices. Furthermore, health professionals belong both to their professional organization and the wider public, which means that lay knowledge could meld with professional understandings at the boundaries of each individual's professional knowledge. When describing their uncertainties and the boundaries of their knowledge, the professionals whom I interviewed related their professional role to their work and personal experiences.

Government policies, medical knowledge, and personal lives constitute parts of a social context that contributed to the conflicting and prevailing "matrix" of norms and morals within which health professionals were situated and from which they provided an account (Butler, 2005: 7). Judith Butler (2005) explained, an "I" attempting to account for oneself is already situated within a social and historical context beyond what it could possibly narrate (p. 8). Health professionals' accounts hinted at the experience of being situated between medical discourses, personal experiences, and skeptical discourses about vaccines. Some interviewees left the limitations in their knowledge about vaccines unacknowledged, whereas others openly shared the

limitations of their knowledge as either implicit to their practice or evidence of their thoughtfulness.

During interviews, health professionals gave what Judith Butler (2005) called an *account of oneself* by attempting to persuasively articulate their professionalism. Butler (2005) argued that any attempt to provide an account of oneself requires appealing to the other who demanded the account and to widely upheld norms and morals:

The 'I' does not stand apart from the prevailing matrix of ethical norms and conflicting moral frameworks. In an important sense, this matrix is also the conditions for the emergence of the 'I,' even though the 'I' is not causally induced by those norms (Butler, 2005: 7).

Indeed, humans are inseparable from our surrounding social milieus, which condition our existence, and our perception of our social positions. In addition to that milieu, professionals are responsible to professional organizations and guidelines, which influence their accounts, perceptions, and actions (see Abbott, 1988). These organizations guide professionals in ways that maintain the legitimacy of the profession as a whole and present homogeneity in viewpoints even where some diversity exists (Abbott, 1988).

One of the ways that previous literature has identified the production of this homogeneity is through an illusion of certainty. Health professionals are situated within a professional culture with a tendency to articulate an illusion of certainty when confronted with abstraction, limitations, and gaps. In addition, health professionals' status, professional perspective, and aversion to risk (both of potential harm to patients and litigation from patients) structure what they observe in their practice as well as their flexibility in presenting their opinions (see Beck, 1992; Lankshear et al., 2005: 361). As such, previous research suggests that health professionals

often present their accounts as though they work with facts exclusively and underemphasize how theories influence health decision-making (Gillett, 2003: 727-728).

Most interviewees expressed such certainty with their opinions of vaccine related decision-making. With certainty in their preferred actions, they explored the boundaries of their knowledge without threatening their presentations as professional healthcare providers. In their accounts, professionals adhered to premade narrative structures (including the *Alberta Immunization Strategy*'s guidelines) about what health professionals do in relation to vaccines. Nonetheless, aside from Public Health nurses, vaccine administration and counselling was underemphasized in interviewees' scopes of practice.

This chapter addresses how interviewees accounted for their vaccine knowledge as health professionals who are situated within a broader social context. Below, I first expand on how Butler's (2005) book, *Giving an Account of Oneself*, and other academic work about narrative influenced this chapter. Second, I relate government guidelines to health professionals' roles. Then, for the majority of this chapter, I analyze health professionals' accounts of their own uncertainties about vaccines, and how their accounts implicate the "other." For instance, health professionals shared their own uncertainties alongside claims that vaccination in general was an integral public health initiative. Some interviewees positioned themselves as informing naïve patients. Others explained their personal concerns about vaccination, which heavily focused on concerns about the annual influenza vaccine. Finally, accounts commonly included typologies of patients who required different degrees of counselling or an account of one's previously held beliefs about vaccination.

### Analysing accounts of the professional self

Accounts of oneself involve responses to a request from "the other" who demands some explanation of who one is. In demanding some explanation of oneself, "the other" makes the speaker responsible for explaining his or her existence and actions (Butler, 2005: 88). Even so, accounts of oneself can only inadequately explain the self, due to the context and limitations of self-knowledge, language, widespread understandings of events, and norms (Butler, 2005). No single account can be "true" because they are all based on one's emergence as a reflective being, with a limited memory, and within a context that preceded one's existence (Butler, 2005: 38). Accounts are also incomplete because we rely upon memories that are to some extent fictionalized, constrained by language, and which the other can only incompletely recognize (Butler, 2005: 39, 42). People give inconsistent responses when asked about our origins (Butler, 2005: 37).

The act of speaking produces the "I" in response to the "other" who has asked about their origins. Indeed, any effort to provide an account creates a fictionalized self through narrative that is based on one's ability to remember, interpret, and voice an answer for the other (Butler, 2005: 39). Any account of oneself, however, inevitability fails to produce an accurate and transparent rendition of a subject: "What is produced in discourse often confounds the intentional aims of speaking" (Butler, 2005: 51). The "I" can never be wholly understood by the person giving an account, which means that any account will be incomplete. Any demand for an account of the self, therefore, involves a degree of violence because it demands the inevitable fragmentation that results from attempts to provide an ethical response, which can only fail (Butler, 2005: 40, 43).

Furthermore, many aspects of the "self" remain somewhat beyond self-knowledge, vernacular presentations of self, and others' interpretations of those presentations (Butler, 2005: 19). Because the self can only be partially recognized, "otherness" remains present even when providing an account *to* oneself. Butler (2005) asserted, "I am always other to myself" (p. 27). Likewise, the self may be inconsistent or may change in ways that one realizes very slowly. Leslie Bloom (1996) argued that subjectivities are *nonunitary* in that they are dynamic, inconsistent, and constantly transforming in relation to language, social interactions, and experiences (p. 178). That is, people may lack the unified self that they present when providing an account. Some people manage such inconsistencies with a fictionalized and simplified account of the self, which may include evidence of their nonunitary subjectivity. Despite nonunitary characteristics, narrators often present themselves as though they are unified in part because of their social context, which includes genre requirements and general plotlines.

These plotlines and genres are only one aspect of the social relations that structure an account. Any narrative cannot be wholly individual or personal (Maynes, Pierce, and Laslett, 2008: 78). Indeed, the autobiography of the self is also a biography of the other, which offers immense insights into relationships (Day Sclater, 2003: 322; Smith and Watson, 2010: 216). Presentations of self are implicitly social in their relation to norms and others (Butler, 2005; Squire, Andrews, and Tamboukou, 2008: 6-7). Any presentation of self or account of oneself cannot stand apart from the social conditions within which it emerged, nor can it stand apart from "the other" to whom one speaks (Butler, 2005: 7, 15). Butler (2005) argued that giving an account "draws upon narrative voice and authority, being directed toward an audience with the aim of persuasion" (Butler, 2005: 12). Consequently, directing an account towards an audience implies that account emerges from the aim to utter a believable and responsible narrative about

oneself. In this project, health professionals offered accounts to persuade me of their professionalism in the context of their professional lives, surrounding milieu, and a research interview. These accounts may be similar to accounts that they would offer to different people, but I am unsure to what extent the circumstance of the interview conditioned interviewees' narrations.

Even without fully constraining or deciding what form the ethical subject will take, normative discourse creates the capacity of the subject to recognize and to become recognized (Butler, 2005: 42). One may realize these limitations through reflection about the norms and language that mediate the presentation of self and adapt one's account to whatever extent one finds possible (Butler, 2005: 26). As such, some flexibility exists within these constraints. Butler (2005) paraphrased Foucault: "Although the regime of truth decides in advance what form recognition can take, it does not fully constrain this form" (p. 22). Norms offer social regimes of truth; they do not dictate, but govern the ways in which one can provide an account of oneself, and language prevents a full articulation of the self (Butler, 2005: 24, 26). For this project, interviewees related their accounts to medical knowledge, professional training, and cultural phenomena—including discourses about vaccines, patient consent, and parental freedom in health decisions.

Heller (2008) demonstrated that understanding vaccine discourse as a cultural phenomenon permits insight into the operation of narratives for purposes of power, interest, and utility (p. 8). Because vaccines gain meaning through narrative, they have diverse meanings for different temporal periods, contexts, and speakers. Indeed, health professionals' accounts include interpretations of their past and place through a culturally and historically specific present that is central to the narrators' subjectivity (Smith and Watson, 2010: 31). Health professionals'

subjective perspectives demonstrated inconsistencies that can emerge while grappling with various issues (i.e., relationships between different healthcare professionals, different forms of knowledge, and patients in specific contexts that increasingly acknowledge medical uncertainty, value informed consent, and accept patient-centered care over medical paternalism [Bleakly, 2003: 186; Griffiths et al., 2005; Marelich et al., 2000: 101]).

Rather than expect the formation of a cohesive self-presentation, this chapter uses contradictory and fragmented statements as accounts or presentations of self. Given the length of my interviews, I can generalize only to the short stories or stock images that interviewees compiled in their accounts. I have taken each account to represent one of numerous possible presentations of self and of professional presentations that interviewees will utter throughout their lives. I analyzed justifications of uncertainties and knowledge gaps in comparison to presentations of others' uncertainties about vaccines. I explain how health professionals' accounts were performances of their professionalism, which included recognition of the gaps in their knowledge.

# **Accounts of professionalism**

Health professionals provide accounts from their social position between experts and the public, which relates to their accounts of patients' beliefs and some of the stories circulating throughout public discourses (Kitta, 2012: 119). Stuart Blume (2006) problematized how the dichotomization of vaccinators and anti-vaccinators erroneously places health professionals "behind a banner of reason." As Blume (2006) suggested, this "banner of reason" appeared problematic in terms of how professionals talk about vaccines. Many interviewees' accounts of

635).

<sup>&</sup>lt;sup>53</sup> Blume (2006) argued that even labeling anti-vaccination as a "movement" could miss patients' concerns regarding immunization because the number of parents who actually hold alternative beliefs about vaccines is incredibly low compared to the number who refuse to immunize (p.

their professionalism included information that others might classify as non-expert or irrational. In some instances, professional accounts lapsed into more personal accounts when different social roles (such as parenthood) and forms of knowledge (such as personal experience) appeared to influence their statements.

Thus, interviewees' understandings of scientific evidence were socially situated. Butler (2005) problematized the presentation of science as removed from subjective socio-historical contexts that could weaken its claim to *truth* (p. 117) or expose certainty as somewhat illusive. Similarly, medical science and medicine are increasingly situated within a culture of consumerism, patient choice, and widely available information. These influences align with professional concerns about how informed and how much choice is ideal for patients (see Gigerenzer, 2003). Furthermore, despite (or because of) its specialized knowledge, the medical profession has faced somewhat of a legitimation crisis during the twentieth century (Prior, 2003: 43). With vaccines, the professionals I interviewed were situated between experts and lay people. This social position means that even the most competent professionals in my sample may need to research responses if patients want nuanced information about vaccines because they have practical rather than esoteric knowledge in that area. Most interviewees provided accounts that appeared to respect their professional boundaries while maintaining the legitimacy of medical discourses surrounding vaccines.

# Government guidelines

Vaccines prove their effectiveness through the lack of disease, which means that when vaccines are effective, their effects can go unnoticed. Their purpose in countries that have largely eradicated vaccine-preventable diseases is to maintain the absence of those diseases.

Alternatively, vaccination failures and inadequate levels of immunization manifest in visible

disease outbreaks. In Canada, most vaccine preventable diseases peaked before 1955 (PHAC, 2006a). Nonetheless, Alberta experienced outbreaks in recent years (Franklin, 2015; Mertz, 2015; PHAC, 2014). The year I interviewed health professionals, the province experienced measles, pertussis, and influenza outbreaks. Both measles and pertussis had been relatively invisible until recent years, although influenza outbreaks remained an annual event. With this disruption to the invisibility of some preventable diseases, some interviewees questioned the efficacy of specific vaccines whereas many attributed outbreaks to waning vaccination rates and population immunity.

In response to recent outbreaks, government guidelines targeted patient compliance with vaccination schedules. Both the *Alberta Immunization Strategy* and the *Canadian Immunization Guide* repeatedly emphasized the benefits of vaccines and took for granted that health professionals would support vaccines. These documents presented problematic beliefs about vaccines as though they emerged from the population. The emphasis in these guides on vaccine hesitancy and education implies that most vaccine noncompliance results from intentional responses—(mis)information from a variety of sources that emphasize or hyperbolize vaccine risks. The *Alberta Immunization Strategy* states, "Misinformation about immunization is readily available. Attitudes and beliefs have a power impact on decisions that are made about immunization, especially for higher socio-economic groups and certain religious/community groups" (Alberta Health, 2007: 19). The *Canadian Immunization Guide* is less bold in identifying who is most likely to trust vaccination misinformation, but it repeatedly states that

people may doubt vaccine safety and necessity because they rarely see the diseases that vaccines prevent (PHAC, 2006: 3, 30, 38).<sup>54</sup>

These guides presented problematic beliefs about vaccines as entirely unrelated to medical discourses and professionals' interactions with the public. For instance, the *Canadian Immunization Guide* included a table titled "Immunization Truths," which reiterated the dominant vaccine narrative that vaccines eradicated disease, emphasized vaccine safety, and then stated the risks of diseases re-emerging due to dropping vaccine uptake rates. Comments throughout both guides highlighted the prevalence of vaccine rumours.

Moreover, the fourth point in the "Immunization Truths" section dispelled a common rumour: "Vaccines do not weaken the immune system. Rather, they harness and train it [...]" (PHAC, 2006a: 31). "Part 2" of the *Canadian Immunization Guide* was devoted to vaccine safety, the surveillance and immediate response to adverse effects, and allaying common fears about vaccines. Likewise, "Table 4" in this guide summarized irrational fears about immunizations and "Table 6," which was three pages long, dispelled suspicions of specific vaccine contraindications (PHAC, 2006a: 71). Small segments of the document rejected fears that some health professionals I interviewed called "misinformation," while most of the Canadian guide referred to the "true" risks of immunizations (allergic reactions, temporary localized side effects, the loss of efficacy if vaccines are inappropriately stored, and so forth).

The *Alberta Immunization Strategy* listed access to immunization as a leading barrier, but second was clients' beliefs, and third was health providers' knowledge and resources (Alberta

<sup>&</sup>lt;sup>54</sup> As a solution to possible ambivalence about vaccines, the guide recommends that health providers learn to communicate effectively and adequately discuss risks with patients and parents (PHAC, 2006: 29). Despite the emphasis on population misconceptions, a substantial portion of the guides is devoted to statements of vaccine safety, which could reassure health professionals (who comprise part of the population) and offer professionals possible responses to patients' concerns (PHAC, 2006: 17, 31, 59-72).

Health, 2007: 9). The provincial document stated that health providers "require time and resources for role modeling and knowledge transfer to new health professionals, and for counseling clients about immunization" (Alberta Health, 2007: 9). By omission, the guide presumes that health professionals who are not "new" are knowledgeable and intent on sharing information. This guide mentioned, but offered less detail about "misinformation" (Alberta Health, 2007: 19). Both documents assert that health professionals' efforts to educate patients could increase vaccine uptake. Nonetheless, a contradiction in this assertion is that the most affluent segments of the population, who are most likely to refuse vaccines, are often the most educated.

## Accounting for the boundaries and diversity of professional knowledge

Ambiguity remains with some of medicine's greatest successes. For instance, although the smallpox vaccine was central to the eradication of that disease, the extent to which containment and surveillance enabled that eradication remains unknown (Strassburg, 2001: 260). Indeed, certainty remains elusive. Some professionals may perform certainty as a means to demonstrate their legitimacy as individual and unified practitioners. Nevertheless, many interviewees accounted for gaps in medical knowledge as something that was unavoidable and expected in their profession.

Those I interviewed who discussed their uncertainties often cited uncertainties that stemmed from the limitations of medical science as a reason that they believed some vaccines lacked efficacy. Butler (2005) implied that such limitations were inherent to science because scientific knowledge is neither transhistorical nor purely objective (Butler, 2005: 117). Butler's (2005) statements refer to science in general, but are relevant to the medical sciences that intend to

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<sup>&</sup>lt;sup>55</sup> See Chapter Three.

inform the health professions. Rather than pure objectivity, medicine backs its claims to a large extent with its own authority and its domination of the health professions (Abbott, 1988). Similarly, some interviewees argued that rather than gaps in their personal knowledge, the limitations of medical science had initiated their uncertainty.

As I discussed in Chapter Four, many interviewees accounted for professional knowledge with examples of what they knew about vaccines, assurance of their confidence in vaccines, and at least modest awareness of current issues pertaining to vaccines in Alberta. Some interviewees spoke as though their perception of vaccine risks was impossibly free of social and cultural influences. Nevertheless, even professional and expert knowledge remains a fluid, "changing product of social activity" (Douglas and Wildavsky, 1982: 192). Health professionals who recognize this fluidity may reserve some doubts.

Alternatively, some professionals may simply be less informed. Kai, who is a family physician, accounted for herself in relation to other physicians who she presented as less informed. Specifically, she said that she knew pediatricians who were unaware of which vaccines were included in Alberta's vaccine schedule. Another family physician demonstrated a gap in his knowledge (or a slip in his memory) regarding vaccine-related events. I asked Rayan, a family physician, about the recent measles outbreak in southern Alberta, he stated, "I didn't know [...], now I'm getting the news from you. [...] Measles outbreak, I didn't know." This unawareness may represent the concessions that busy health professionals make when attempting to remain up-to-date in multiple topics. This unawareness, however, also demonstrated that Rayan prioritized qualities other than remaining up-to-date with vaccine related events when he gave his account.

Others gave accounts of boundaries in their personal knowledge that emerged from the breadth of knowledge that related to their medical practice. Ren summarized his efforts to remain informed: "it's like drinking from a fire hose today trying to keep up with healthcare issues, right, and everybody's area thinks they're the most important area and it's changing really fast." He said he could find information when necessary, but that the details were beyond his immediate memory. Regarding his knowledge about vaccines, he elaborated about his knowledge: "It's good and it's comprehensive and it's available, but where my working knowledge functions on a day-to-day basis at the clinical interface, I don't carry that. I'd have to go look that up."

Overall, interviewees' accounts clarified that their role involved accepting dominant medical perspectives. For instance, Adel, who is an urban family physician, explained that her memory of her training about childhood vaccines was slowly fading over the years because her role primarily involved informing adults about their vaccines. Instead of knowledge, Adel accounted for her acceptance of vaccines:

I wouldn't be the kind of physician that would go look at that study and look at it in depth and decide on the pros and cons of the study. I'm the kind of physician who would go with more of the mainstream (Adel).

Many interviewees accounted for their own lack of knowledge or fading memories by stating that they lacked time to research everything. They positioned their allegiance to medical discourse as evidence of their professional practice.

Several health professionals said that they relied on Public Health nurses to inform patients, whereas others stated that they pursued various means to improve their vaccine knowledge.

Health professionals, who were not Public Health nurses, placed their knowledge between the public and vaccine experts. Some health professionals told me that, like the public, they learned

most of the details that they know about vaccines through parenthood and Public Health nurses rather than through professional training. For example, Kian explained that he researched vaccines when he had his child:

I didn't really have an opinion about [vaccines] really until I had my own child. Then I had to solve the issue for myself. It didn't take me long [...]. I just looked up basic research, and especially when you study cohorts of children not vaccinated with the illness, cohorts of children vaccinated right? And you watch even the side-effects disappear into oblivion, right? [...] So it was pretty quick for me (Kian).

Publicly available discourses and suspicions likely influenced Kian's perceived need to research vaccines. Even so, the result of his research was that his child was "vaccinated and on schedule."

All the health professionals whom I interviewed expressed support of the dominant vaccine narrative, but they detailed some contradictions. Most contradictions were small (e.g., some interviewees said that although they wish patients would be fully vaccinated, they emphasized the rotavirus or varicella less than other vaccines). In other cases, contradictions appeared to be substantial. For instance, some interviewees stated that the influenza, Zostavax, or other vaccines were less beneficial than the costs or risks associated with them. Some physicians explained that they refused specific vaccines or saw no value in their administration, and then they accounted for how their suspicions of specific vaccines were informed. Furthermore, such accounts bracketed specific vaccines off from their general support of the grand vaccine narrative. By bracketing off uncertainties about specific vaccines, they maintained sweeping supportive statements about vaccines.

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<sup>&</sup>lt;sup>56</sup> Some interviewees prioritized vaccines based on their perception of the risks associated with the vaccine or the respective disease. For instance, Mona, who is a pediatrician, explained that she did not emphasize the rotavirus vaccine because "most kids who get [rotavirus] will not be affected significantly by it." When I asked about which vaccines she did prioritize, Mona grounded her opinions in her professional experiences by explaining her experiences with diseases that she represented as deadly. In addition, she described the health consequences for other vaccines that she supported.

Interviewees justified their uncertainties in ways that affirmed their professional status, but their explanations for other's uncertainties fell short of such maintenance. As a result, I interpreted interviewees to be presenting their own uncertainties and even doubts as acceptable, whereas they presented most others' uncertainties as symbolic of shortfalls in their knowledge. Interviewees' accounts included uncertainties about waning immunity, the cost-benefit-analysis of vaccines, the role of pharmaceutical industries in vaccine promotion, and the prioritization of specific vaccines over others. Kian, who I mentioned above, discussed each of these topics in a continuous account. He demonstrated particular awareness of the boundaries of his knowledge and presented his uncertainties about vaccines as professional reflexivity. I overview his account before explaining how these themes appeared in other accounts.

#### Kian's account

Butler (2005) wrote that all accounts attempt to persuade (p. 12). Likewise, Kian utilized his skepticism regarding vaccines as evidence of his professionalism, rather than evidence against it. Kian was a young rural family physician. He told me about his unvaccinated brother contracting the mumps and his mother's family being mostly unvaccinated. It appeared that Kian first learned about vaccines as a child in a family that may have placed limited value in vaccines. As an adult and physician, Kain conducted his own research and had vaccinated his children, but he freely shared knowledge gaps with me, which he related to his perception of the limitations of medical knowledge. The excerpt that follows is broken with my commentary, but during the interview, Kian shared the entirety of this narrative without interruption.

Kian explained his support and adherence to the vaccine schedule. He identified physicians who refuse vaccines as "others" who are subject to suspicion and regulation:

[...] all my kids are vaccinated on schedule. I've never met a doctor in Canada who was against vaccinations, and my patients are so surprised to hear that. There's this myth out

there that the average doctor doesn't vaccinate their own children. I did meet one doctor in the United States that wouldn't vaccinate. But he had to move from state to state presumably because of violations of local health laws. I don't know, but he was very against vaccines.

Kian separated himself from "others" who were unsupportive of vaccines, but asserted that along with himself, most of those in his profession supported vaccines. As he continued, however, he demonstrated that he found some vaccines successful despite his uncertainty of others.

Kian critically reflected on medical discourse and his profession. He explained how medical discourse inadequately addressed chickenpox immunity:

I'm not necessarily a firm believer in the Western medical system either. I don't necessarily agree with vaccinating for chickenpox. I think it's a bit of a poor experiment. I think that chickenpox is a miserable virus and immunity to chickenpox should be maintained as strong as possible. And there is some data suggesting that the immunity to chickenpox virus hasn't declined or it began to decline already before the vaccine. And the way you see this is the shingles rates. So, the rate of shingles is going up. In fact, I'm sure I had five teenagers with shingles in the past year, so the easiest explanation, the most intuitive for me, is that they had latent chickenpox virus, but now they have reduced immunity and to the chickenpox virus and so it exhibits itself as shingles. [...] and why is their immunity to chickenpox reduced? It's because they aren't exposed to it anymore. So it used to be that chickenpox was considered lifelong immunity other than the unfortunate few that got shingles when they were older, but that may have been due to repeated exposure to young children with chickenpox because it was always going around. So, you got repeatedly exposed and your body would remember and you'd build up cellular immunity to that and maintain it.

In this segment, Kian provided a medical explanation about the shortcomings of the varicella vaccine (chickenpox). In contrast to Kian's critiques, Canada's National Advisory Committee on Immunization (NACI) estimated that this vaccine has resulted in improved health and cost savings compared to the 350,000 cases and 1,550 hospitalizations that occurred from chickenpox

in the years before varicella was included in the immunization schedule (Crompton, 2015: 4). When Kian expressed misgivings about the Western medical system, I was unsure whether he was referencing the pharmaceutical industry, which he elaborated about. The primary concerns that Kian highlighted were what he interpreted to be an over-reliance upon pharmaceuticals to inadequately manage health issues that he argued could be addressed less invasively through lifestyle changes, such as dietary changes.

Kian continued his account by bracketing off the vaccines he was unsure of, but offered knowledge about the importance of vaccines in general and listed examples:

I think one should vaccinate carefully. Some things are [...] an easy sell for me, you know, haemophilus influenza B, oh highly successful vaccine rate, polio, measles, mumps—mumps not so much—but rubella for sure. I'm not necessarily convinced of the vaccinating for all the strep, pneumonia serotypes. There's some evidence that suggests different serotypes become more prevalent in response to vaccinating against other ones. So, I'd need to see more research on that before I'd be totally convinced.

He accounted for his skepticism in relation to knowledge he presented as medical rather than as pseudo-scientific. He articulated his perspectives in relation to his professional knowledge and his experiences with specific patients rather than amidst anti-vaccine discourses.

When Kian reflected on pharmaceutical influences, he melded his position within both the public and professional contexts. His skepticism of influenza vaccines and the pharmaceutical industry in general demonstrated reflexivity about the limitations of medicine:

I have huge issues with pharmaceutical influence in drugs and vaccines and I don't tend to get the flu vaccine because I don't believe in it myself. It's not something I'm vocal about, but I think that the efficacy of the vaccine is too low, and I tend to question the mortality rate from the flu. In clinical medicine for five years and I have yet to write it on a death certificate, and I fill out lots of death certificates right, so the idea that 20-50 thousand in North America people die of the flu. I just don't believe it. I don't see it so

it's hard for me to believe that it's true. I've tried to look where these numbers come from, how do they compile these statistics, it's difficult to find. So, in the end, I assume that there's some bias affecting this somewhere. [...] And I don't understand why people have been made afraid of the flu, I think it's just ridiculous and it's completely manufactured. Without the media or something, I don't understand the fear of the flu. Why would people stampede flu clinics? Right? [TM laughs] Young healthy people.

The year I interviewed Kian, Alberta reported an increase in lab-confirmed influenza of 35% from the year prior (Government of Alberta, 2014: 4). The 2014-2015 season saw a massive jump in flu-related deaths to 103 (as opposed to the annual average of 30-40 deaths [CBC, 2015a]). Physicians whom the *CBC* interviewed about influenza related deaths explained that in the 2014-2015 season the H3N2 virus had mutated such that it mismatched the influenza vaccine (CBC, 2015a). I did not prompt Kian regarding these statistics, so I am unsure how he would explain these deaths aside from saying that they were more than he would attribute to influenza.

Yeah, so that's, so I'm not an easy sell on vaccines. [...]

As Kian continued his account, he explained that occasionally becoming ill was potentially beneficial despite the fear mongering about the dangers of disease:

Kian: For one, sometimes I think that getting the flu may not be such a bad idea. Flus change all the time, the more flus you're exposed to, statistically, the more likely you'll be more immune to the next one. Some of it is just personal experience with the flu, having never really had it.

TM: No?

Kian: No. No so it might change. I saw enough people that were very ill with H1N1 that I did get the H1N1 vaccine; it obviously was a flu with fairly high valiance. And, fairly obvious to me in clinical practice. So I thought it was, and because it was a fairly busy time for me and had a lot of work to do, I thought, well, this is not something this time I want to take my chances on, right, so I was vaccinated on it, but the efficacy of the flu is probably less than half, published opinion, right? I think that it's completely over the top

to try and make it mandatory for healthcare workers to be vaccinated for the flu. But that's just, they'll need better data before they can convince me.

In this segment, Kian appeared to situate himself between medical expertise and the public. Nonetheless, he insisted that it was "irresponsible" to refuse vaccines for children. In doing so, he aligned himself with dominant perspectives within his profession. As such, his account offered persuasion of his professionalism, personal reflexivity, and support of dominant medical discourse. Without aligning himself with the dominant discourse, Kian would compromise his professional legitimacy (e.g., this is how Dr. Andrew Wakefield lost his medical license).

Butler (2005) explained that an account of the self is always in relation to the other. Kian related his account to the "other" (myself) and to social norms by asserting that responsible parents vaccinate their children. Yet, he demonstrated reflection as a parent and health professional by presenting "others" with suspicions of vaccines are relatable and potentially reasonable. Kian shared his own uncertainties about vaccines, but emphasized that those uncertainties were irrelevant to his decision to use most vaccines.

In what follows, I detail how the topics that Kian introduced appeared in various other interviews. First, Kian talked about an uninformed American physician. Other interviewees mentioned how they were informed about vaccines, but they knew of professionals who lacked such knowledge. That is, they provided accounts of themselves in relation to other physicians and to vaccine skeptical patients. Second, Kian expressed concerns about the overreliance on pharmaceuticals. As I discuss in the following chapter about risk and Cost Benefit Analysis, other interviewees' accounts involved questioning the necessity of some vaccines and uncertainties to the role of pharmaceutical companies. Third, Kian expressed uncertainty about the necessity of specific vaccines and prioritized some vaccines over others. Other interviewees shared similar uncertainties or included personal accounts of vaccine refusal, especially with the

influenza vaccine. Fourth, Kian stated that many patients had reasonable concerns about immunization. Similarly, many interviewees explained that there were several types of patients who they counselled in different ways. Lastly, Kian mentioned learning about vaccines through his role as a father more so than as a physician. Several interviewees also explained how their understanding of vaccines had changed throughout their lives.

#### Accounts of oneself and the other

Butler (2005) explained that any account is limited in its intelligibility to the other, but also created in relation to the other and to norms (p. 33). Indeed, accounts of oneself provide an articulation of identity, which is relational (i.e. constructed in and from relationships with others [Eakin, 1999]). For example, some interviewees accounted for themselves as a group of professionals by using "we" rather than "I." In this way, these interviewees attempted to produce themselves as belonging to a homogenous group of professionals, and in doing so, presented the members of that group as interchangeable. Nonetheless, the inability to explain the self fully and for others to fully interpret the explanation means "any effort to identify fully with a collective 'we' will necessarily fail" (Butler, 2005: 34). Some interviewees managed this failure by juxtaposing their own uncertainties about vaccines to those of others. In this way, they asserted their knowledge about vaccines in relation to others who purportedly lacked knowledge. These interviewees provided accounts of others who refused vaccines, of the limitations of pharmacy or government, and of their knowledge of health professionals who were uncertain about vaccines. In this way, accounting for those who were outside the norm appeared to position an account within the normative discourse regardless of personal uncertainties about vaccines.

For instance, Chandra acknowledged the diversity of opinions regarding childhood vaccines both within her profession and the broader public:

[T]here's a diversity of opinions. I think that if you look at the public, their uptake of immunizations is perhaps waning over time. Even for what we consider routine childhood immunizations [...]. But, even amongst healthcare providers, for example I think that Alberta Health Services has data on the lack of uptake of flu shots for example amongst healthcare workers. So, I don't think it's just the public that voices their concern or their discontent. I think healthcare providers themselves are if you look at what they do, not only what they say, there seem to be some issues there that need to be looked at (Chandra).

Chandra stated her support for all vaccines, but expressed thoughtfulness about exceptionally rare risks, and related her understandings to those of other professionals. Accounts such as this one included opinions, beliefs, and potential uncertainties that vaccine guidelines overlook.

Likewise, Chandra and some interviewees accounted for uncertainties about the long-term efficacy of vaccines, which I interpreted as evidence of the persuasive accounts of thoughtfulness regarding potential gaps in medical knowledge. For instance, Chandra questioned whether Alberta's recent outbreaks had resulted from an increase in vaccine refusals or from the efficacy of vaccines:

So first, around efficacy, I think there are misgivings that things are not as effective for a lifetime as they may have initially been described. And so, when you see waning immunity, I think that causes people pause and they think, 'but this isn't what I was told, why is what I'm seeing different than what I was told? And how much does this make me question the rest of what I was told? If this one thing isn't true, what else isn't true?' So, it makes people question the evidence base behind them (Chandra).

Chandra accounted for her opinions by describing her professional training, medical knowledge, and how the limitations of medicine can be hidden from the public. As such, her account seemed to aim to persuade me that her understandings of vaccine uncertainties were based in thoughtfulness and professionalism.

Monica, who is a family physician who practices in rural and urban settings, elaborated about how immunity could drop throughout one's lifetime. She stated that many of her pregnant patients lack immunity to specific diseases:

I do a lot of prenatal care and I've noticed a huge number of the pregnant women who I see are not immune to measles, mumps, and rubella, and a lot of them--they have been vaccinated. It's just their immunity levels have waned. And [...] kind of my own theory, but I wonder if that was part of the issue [...] There are a lot of adults whose immunity just kind of waned [...] below immune levels. And that in combination with the push-back against getting [...] vaccinated at all is causing some of the outbreaks (Monica). Monica's account contextualized her medical knowledge with what Collins and Evans (2002) called "experiential knowledge" (her observations of patients who lack immunity). Her account problematized the assumption that vaccinated bodies have lifelong immunity.

In contrast, however, to their own thoughtful uncertainties, most accounts of others' vaccine ambivalence presented those others as misinformed or otherwise unaware of medical perspectives about vaccines. Such accounts reflected on their past selves as uneducated, other professionals as less informed, and patients as lacking accurate information. Health professionals situated their own uncertainties as reflexive professional opinions about what is best for individual patients rather than as contradictions in their understandings. Moreover, interviewees maintained boundaries between their accounts of self and their presentation of others.

Aalia made this boundary clear when she explained that she was certain of the necessity of each vaccine, but understood how vaccines can be targeted in attempts to understand medical conditions that have eluded medical science:

There are many things there are rising rates of and vaccines are an easy one to blame it on because it's so widespread. So, it's easy to say, well, all these kids who got vaccinated got this and this when it's just a sort of a population change for other reasons (Aalia).

Aalia accounted for her confidence in vaccine efficacy and safety as more extensive than some healthcare professionals and the public. She portrayed herself as particularly well educated about vaccines by stating that she pursued supplementary education and that her father worked in Public Health. Yet, she was aware of others' ambivalence. (She, however, also expressed inconsistency when she expressed uncertainty as to whether the chickenpox vaccine could be linked to a perceived rise in the prevalence of shingles.)

## Accounts of Oneself and Influenza

Most health professionals expressed support for all vaccines, but then many demonstrated ambivalence about specific vaccines. For example, about one third of the physicians I interviewed questioned the efficacy of the influenza vaccine. Several interviewees said that they had refused the influenza vaccine in the past, three physicians stated that they had forgone that year's influenza vaccination, and two had accepted their first influenza vaccine that year. Any account is situated within a set of relations and norms (Butler, 2005: 8). In their accounts, these interviewees presented themselves in relation to norms associated with the health professions as well as a consumerism model of healthcare. As such, some interviewees appeared to grapple with similar issues as their patients when deciding whether the flu vaccine best suited their needs.

As a health consumer, Johanna accounted for her refusal of the flu vaccine with a narrative that is common to many lay people. Specifically, she talked about becoming sick on two occasions following immunization. She glossed over her alternative treatment plan to avoid the flu virus, which included B-complex multi-vitamins and "lots of fluid, lots of vitamins, lots of rest. I try to work less then." In this account, her evidence resonated with popular discourses more so than scientific evidence. But, she shared these discourses from the authoritative position

of a physician. As such, her personal account and professional account partly blurred together into the unique health decisions that she argued meets her needs.

Some interviewees presented the flu virus as differing from viruses that they described as riskier. For instance, Mariam refused to be audio-recorded because of her strong feelings that childhood vaccines were necessary. Yet, she stated that she only pushed the flu vaccine for highrisk populations (asthma, elderly, etc.) and that she herself had refused it. She explained her belief that the flu virus was very rare and people mistakenly call everything the flu. In her account, Mariam likely relied on dissenting medical expertise, and/or her experiences with the flu virus. Indeed, scientific and pseudo-scientific investigations of the influenza vaccine have generated various perspectives. For instance, Peter Doshi is an assistant professor at the University of Maryland's School of Pharmacy who has expertise in medical anthropology. Doshi recently published critiques of the influenza vaccine that appear in such prevalent medical journals as *The British Medical Journal* (Doshi, 2013). Doshi's article appeared in both supportive and critical news and social media outlets (Salzberg, 2014). Doshi has a PhD in history, anthropology, and the study of science, technology, and society rather than in medical or clinical research. Much of Doshi's work offers valuable critiques of healthcare related problems, such as the influence of pharmaceutical companies on medical practice. Nonetheless, articles from academics who appear to be authoritative in medical science could appeal to patients or even to some professionals from the medical sciences.

In fact, popular critiques can become engrained within health professionals' accounts of their own knowledge and uncertainties. For instance, an urban family physician, Faris, explained that he never received a flu vaccine because he believed his work environment created immunity:

[...] there is no real reason, but because I think [...] I'm already immune, given a long period of contact with people, right? [...] So I said, 'What's the point?' Yeah, I have never ever had the flu shot (Faris).

Faris experienced feeling healthy throughout the flu season when he was in contact with patients, which confirmed his belief in his immunity. I failed to find medical or scientific statements to support the claim that one could rely on immunity from exposure to patients, but this statement resonated with widely held beliefs about acquiring "natural immunity" from disease exposure. His beliefs seemed to demonstrate how accounts of vaccine knowledge might combine professional training with personal experience.

In contrast to their alternative interpretations of the flu vaccine, Faris, Mariam, and Johanna shared stories that demonstrated their support of most other vaccines. Even so, Faris seemed slightly hesitant about vaccinating his family. Faris narrated about his efforts to dispel a patient's fear that updating her MMR vaccine could compromise her pregnancy. When I asked whether Faris would immunize his children, he sounded less sure than other interviewees. He responded: "Depends. Let me have children first, then we'll have a discussion about it. [laughing]." Faris accounted for his personal decisions regarding vaccination as if they were independent from his medical knowledge and how he counseled patients. His account demonstrated personal apprehension regarding vaccines, which contrasted with many professionals' presentations of their professional knowledge and lesser uncertainties or doubts.

# Accounts of the patient

Health professionals accounted for how they provided information to different "types" of patients. Generally, these accounts listed two-to-four types of patients in relation to expected success from counselling efforts. Interviewees stated that most parents accepted all vaccines (some sub-divided this group to include parents who want to vaccinate but who have difficulty

with access due to scheduling, school absences, or other obstacles). Jasmeen summed up these groups of patients by explaining, "I think that the majority of my patients would get immunized regardless, but I think that there is that little segment that's really not sure and I think for those people it's important." Jasmeen emphasized the importance of discussing vaccines with those who are unsure rather than those who seemed to be opposed or accepting of vaccines. Some interviewees accounted for parents who were uncertain about vaccines and may be open to discussion. Notably, Anita emphasized the importance of discussing immunization with childless young adults before they became pregnant and began researching vaccines. Many professionals stated that some parents who refused vaccines were immune to medical reason. These parents included a minority who opposed vaccines because of religious or cultural practices, those who wish to postpone their childhood vaccines, and those who adamantly opposed vaccination. These accounts usually presented patients who opposed vaccination as uninformed or misinformed, but occasionally as thoughtful and savvy. In all accounts, however, patient choice, advocacy, and education remained priorities.

Nevertheless, the use of such categorizations could hinder some parents' efforts to access information through health professionals. For example, Blume (2006) found that many parents in the United Kingdom were uncertain about vaccines because of the wide availability of conflicting information and their desire to make thoughtful decisions about their children's health. Blume (2006) emphasized that many of these parents understood health professionals to be abrasive when questioned about vaccines and as an obstacle to their informed choice (p. 637).

When I opened interviews with a question about what was the biggest vaccine-related issue in Alberta, many linked "misinformation" to vaccine refusal. Unlike Kian who spoke about himself as sharing some vaccine skepticism with patients, most interviewees identified patients

as particularly susceptible to inaccurate beliefs. Tobias explained his concern about the ongoing prevalence of disproven information that contradicts the necessity of vaccines:

Well, the significant percentage of people that don't want their children to have immunizations because they're concerned about adverse effects. I think the article quite a few years ago, about the association, or proposed association of [...] the measles, mumps, and rubella immunization with autism has affected a lot of people, and even though that has been disproven, it's still in the hearts of people and they're still very reluctant (Tobias, urban).

As such, Tobias accounted for patients' mistaken beliefs by explaining that patients continued to be emotionally susceptible to the erroneous results from widely publicized studies. The idea that these studies remained "in the hearts of people" centered their vaccine ambivalence on emotion, rather than on thoughtfulness, rationality, or (as Tobias said) savviness. Accounts of patients' beliefs often appeared to contrast the professionals' role as knowledgeable or even immune to inaccurate information.

The professionals I interviewed accounted for parents' aversion to *any* perceived risk to a healthy child and, most explained patients' thoughtfulness decisions to refuse immunization. Ren explained:

I think it would be neglectful to make the decision [...] without proper attention given to the question, but if a parent has looked at it and considered it and decided 'no,' the freedom to choose, and I think to choose for our kids is greater than that mandated societal benefit of an enforced immunization. Otherwise, we would have .. a place we would not want to live. [...] Freedom of choice is a strong value, informed consent is a strong value in our profession. If they've been informed and they've decided and they know the information, and they know the risks and benefits, then we should accept their decision. We'll continue to influence, continue to educate, continue to get educated ourself, continue to get more data and more information. Continue to consider their objections and see if we can refute them with medical evidence and present the evidence

when we find it, but we need to accept their freedom to choose I think is a greater value. There's such a thing as natural immunity. Not everybody has died from those diseases the first time around, but not everybody survived either (Ren).

Ren's account valued thoughtfulness as a deciding factor in whether parental behaviours constituted mistreatment. Thoughtful vaccine refusal likely elicits very different responses than the thoughtful refusal of basic medical care. For example, in March 2016, nineteen-month-old Ezekiel Stephan passed away in Lethbridge, Alberta. Ezekiel died from meningitis, which his parents attempted to treat with the help of a naturopath and natural remedies, rather than with established medical treatments (Gibson, 2016). Ezekiel's naturopath and parents appeared to have relied on treatments that lacked scientific evidence, but which likely involved thoughtful planning. Such thoughtfulness is understandable because some medical treatments have eventually proved ineffective or harmful. Furthermore, patients and health professionals alike often misinterpret scientific data. As Gigerenzer (2003) demonstrated, consent often lacks the "informed" component, which means some vaccine refusals are based in a misinterpretation of data.

Accounts about professionalism included both critiques of parents' vaccine choices and opposition to mandatory vaccination. Indeed, when I asked whether they believed vaccine refusal was medical neglect, most interviewees said, "no." For example, Monica compared vaccine refusal to that of other health treatments and issues:

I know there's a kid who was quite obese at age six or something, and I know Child and Family Services were involved in that because the parents were under suspicion of neglect because [...] they were the ones who were feeding the child and giving the child nutrition. So, it kind of falls under that kind of thing too (Monica).

Monica discussed obesity above, but other topics (diabetes management, alcoholism, post-natal eye drops, and so forth) emerged during interviews. Despite arguments that vaccine refusal was

harmful to children's health, interviewees situated vaccine refusals among many issues that created health problems.

Despite their own perception of vaccine refusals, most health professionals emphasized the sanctity of parental freedom and informed consent:

It's personal rights and freedom and I don't think you want to force anyone to do what they don't want to do. And I'm not sure it would help. I think you would still have people trying to sneak by it or get exemption letters, I'm not sure mandatory vaccination is the way to go anyway so (Amaya).

As Amaya explained, mandatory immunization could create other problems for health professionals. Indeed, the limitations of mandatory immunization are easy to observe with the smallpox vaccination (see history chapter). In Amaya's account, professionalism included negotiating "a set of norms and rules" about informing patients and respecting patient decisions in relation to her own knowledge regarding vaccine risks and benefits "in a living and reflective way" (Butler, 2005: 10). That is, Amaya reflected upon options for increasing vaccine uptake, but her reflections were mediated through prevailing medical ethics surrounding patient consent, as well as norms regarding parental choice and neoliberal consumerism.

At an extreme, however, would be the perception of a group of parents who refuse vaccines as grounds for neglect. Some Canadian health professionals who Kitta (2012) interviewed "invoke the legendary motif that children can be taken away from their parents if they are not vaccinated" (p. 97). Unlike Kitta (2012), who found some health professionals fantasized about taking parents to court or having child services take unvaccinated children into protection, professionals whom I interviewed focused on education. Only one pediatrician shared a fantasy about pursuing legal action against parents, and he specifically wanted to pursue action against parents whose children had tetanus after they refused that vaccine. Alternatively, those whom I

interviewed focused on education even when they expressed a strong emotional response to refusals. For instance, Tori explained how measles spread throughout the hospital in her city:

Yes... [...] I consider it irresponsible, like it's, you know, it's not only your child, it's the entire community. You know the incident that we had just a few months ago, unvaccinated child went to Europe, well this whole thing with Lethbridge, right? Comes home, sits in emergency, you know, measles is so contagious, you just have to walk by somebody who has measles and you're at risk, right? You don't have to touch them or cough on them or anything. And we had to give blood products to fifteen babies, sick babies, we have to give them blood products to provide them some kind of protection against measles because you didn't vaccinate your kid. Right? (Tori).

Tori's rendition of patient education was a vivid, personal, and involved reference to real events that harmed people in Alberta. She wished to explain to parents the consequences of vaccine refusals for other members of the community and make those implications understandable.

Some health professionals stated that the need to maintain a positive relationship with patients superseded the need for vaccine compliance. An urban pediatrician, Kellan, cited the tension between paternalistic medical practices and patients' freedom of choice:

Yes. I mean I think that [...] it's not so much that my colleagues would believe that vaccines cause autism or that, you know, that the thimerosal is leading to major toxic sort of brain reactions. I think there is a continuum, though, about how much people are willing to compromise. So I definitely have colleagues who would [...] sort of defer to parents who want to either not vaccinate or postpone vaccination. That they would—rather than, sort of, risk any sort of disagreement—that they would, sort of, back off and let parents make their own decisions. And I think it's a tough one because I think that we want to be respectful and not, sort of, [be] paternalistic about things and allow families to make their own decisions about their kids, and yet there are genuine risks of not vaccinating that ... Again, I feel like people have a range of opinions about how strongly they want to, kind of, send their message (Kellan).

Although Kellan claimed to provide details about vaccine safety and necessity to his patients, he stated his suspicions that some of his colleagues avoided discussing this topic with patients. In doing so, Kellan presented himself as invested in patient vaccine education to a greater extent than his colleagues.

Likewise, some physicians explained that their professional role involved accountability to individual patients more so than to Public Health vaccination goals. Jayne, an urban family physician, explained how patients who pay for treatments—specifically the HPV vaccine for those who were outside Alberta's coverage—were medical consumers who expect results:

When patients get something that's quite expensive—because they're a paying consumer—they actually want something that's going to deliver. They want a justifiable, strong argument for spending that amount of money. See? (Jayne).

Jayne accounted for patient uncertainty by stating that, "nothing is without its risks," but that with the HPV vaccine "the benefits really did outweigh the risks." With her generic explanation that the benefits outweighed the risks, Jayne accounted for the esoteric professional knowledge that was beyond her personal knowledge (see Abbott, 1988: 29) without relying on personal narrative. When I asked for her opinion, Jayne primarily presented what she perceived to be patients' beliefs, although she admitted to having some hesitation when the HPV vaccine was first released regarding its cost and efficacy. For example, she stated, "I'm just following whatever guidelines we're given. I only hesitate if the patient [doesn't] want this." She explained that mothers asked for MMR and DTaP information or that "some patients are happy to have" the Hep B vaccine. That way, she accounted for responsibility to her patients while maintaining her own role as more objective and removed from opinion.

Unsurprisingly, physicians and nurses presented themselves as more informed than most of their patients regarding vaccines. They weighed parental choice and consent against their

perception of the benefits of vaccines. The nurses I interviewed were more likely to question parental choice and consider mandatory vaccines or limitations on free choice as potential solutions to dropping vaccine rates.

Even so, the nurses and physicians whom I interviewed were generally careful to explain that they respected patients' decisions and sought to educate patients rather than force compliance. They accounted their role in relation to parents as empowering parents to make informed choices. Despite statements that some patients were unable to change their minds, interviewees emphasized education as the only solution. Interviewees presented education as any effectively communicated statistics, medical knowledge, or narrative that informed patients of the efficacy, necessity, and risk associated with vaccination. They emphasized that education and accurate information could sway patients towards accepting vaccines even though they suggested some patients were immune to reason. That said, they often presented the choice to vaccinate as the only "informed" option. Moreover, despite their emphasis on thoughtful health decisions, most accounts accepted that some parents made uninformed decisions to vaccinate their children. They accounted for thoughtless decisions to accept vaccines as responsible, but thoughtless decisions to refuse vaccines as alarming and dangerous.

### Accounts of the past self

Some physicians and nurses accounted for previous doubts regarding certain vaccines. They narrated how they had learned to value vaccines more through professional training and experience. Such accounts of the past self created a disconnection between what the professionalized self knows and what the in-training or less experienced self knew. These

<sup>57</sup> Any differences between nurses and physicians with whom I spoke could result largely from my having interviewed about three times as many physicians than nurses.

accounts presented medical knowledge as somewhat esoteric or inaccessible without the professionalization and experience that they since had accumulated.

The influenza vaccine was most commonly cited in health professionals' accounts of their changing understandings. For instance, all nurses stated they had received the influenza vaccine that year, but some recalled questioning it in the past. Naomi, who is an RN in a family medicine clinic, explained that she knew nurses who refused that vaccine. She offered some legitimacy to their refusals by stating that although she complied with the flu vaccine schedule, she previously doubted that vaccine:

Naomi: I know a lot of nurses actually in [town], who—not so much the childhood vaccines, but more so the influenza—A lot of the nurses that I know don't get vaccinated. What they believe that there's just not enough information, not enough research done.

And they still believe that they can get sick anyway. [...]

TM: Ok. And did you ever hold beliefs like that yourself?

Naomi: No. I've always been vaccinated. I mean obviously there's been times that I've questioned it and I was actually vaccinated this year with the influenza this year and I had influenza A, the H1N1. But, I'm still a strong believer in vaccines.

TM: Yeah. Do you think there's a reason you got H1N1 anyway?

Naomi: I guess I just didn't build enough immunity to the vaccine and I was probably around someone in the clinic who was unwell and they weren't masked.

Naomi accounted for both her support of all vaccines and her understanding of other's skepticism, when she stated that she had questioned the vaccine, but was a "strong believer in vaccines." By stating that she "obviously" questioned the flu vaccine, Naomi accounted for other healthcare professionals' skepticism of the vaccine as though it was normal. Similarly, MaKenna stated that she held prior concerns about the flu vaccine. MaKenna said had refused it for herself and one of her three children in the past. In recent years, however, MaKenna explained that her viewpoints had changed and she was "a full believer in it now." She stated the flu vaccine was "a

bit of a gamble," but that it offered enough protection to be worthwhile even if the strains for that year were inaccurately predicted. MaKenna stated that even a flu vaccine that mismatched that year's flu strains would be "60% effective." Financial costs and vaccine-related risks were absent from both interviews. In fact, financial costs tended to appear in interviews only when patients had to cover the cost of vaccination, such as with Zostavax and HPV for specific populations.

These statements accounted for changes in knowledge that can emerge with education and training. The nurses I interviewed claimed that their education incorporated little vaccine training, most of which was optional. As such, their changing opinions could account for their own reflections regarding experience and information that they encounter while working. In addition, they presented themselves as being transformational in that they change over time and in relation to different social circumstances (Bloom, 1996). That is, these accounts of self included the potential to change. In this case, change was either a response to professional training, or overcoming a shortcoming of professional training.

# Accounting for the other professional

The topic of other health professionals' uncertainties about some vaccines appeared to be fairly sensitive. This topic encouraged interviewees to make statements about whether they believed their colleagues fit their understandings of being knowledgeable and professional. For example, Chandra explained how professionals avoided speaking about any vaccine uncertainties that they experienced. She implied that health professionals who hold beliefs that contradict vaccination are numerous, but silent. When I asked if she met any such health professionals, she responded:

I suppose we all have because if the uptake is as low as they say, then all of us work in an environment where most of our colleagues choose not to. [...] Although it's not really discussed at work, I don't really think it's so much, I think it would be false thinking to

think that it's a problem of somewhere else and not an issue in every single healthcare setting across the province. I work in a children's hospital. It's a big diverse place, and yeah, I'm sure there's people who have not had their immunizations (Chandra).

Other interviewees confirmed that vaccine uncertainties were a silent issue. As Dena, an LPN, stated, "I think the healthcare workers are pretty good at keeping a zip on it whether they think it's important or not." Through silence, health professionals can act as if they hold unanimous opinions about how to combat communicable diseases. This false unity could reaffirm public perceptions that "All doctors are equivalent, all nurses are equivalent" (Abbott, 1988: 61). In addition, this silence allows health professionals to attribute vaccine uncertainties to only certain types of other—predominantly the patient.

Many interviewees accounted for other professionals' uncertainties in a way that demonstrated their own knowledge and uncertainties as acceptable in comparison to others. That is, they commented on their own uncertainties about vaccines as though they evidenced *thoughtfulness*, but others' uncertainties as though they evidenced *thoughtlessness*. For example, Javen explained that some family physicians he knew were oblivious to some of the vaccines that are available in Alberta:

Javen: But some other family practitioners I had a discussion with playing golf, they don't know even of the pneumococc vaccine, you know the meningococc. So, they're not well informed.

TM: They don't know it exists?

Javen: Yeah, and they don't know we're giving it [... the] mneumococ vaccine. The pneumococcal conjugate (PCV13) and meningococcal conjugate (Men C) vaccines are provided to children at two months, four months, and twelve months of age. In fact, children only receive one other vaccine each time they receive their PCV13 and Men C vaccines and boosters. In this excerpt, Javen identified others who he argued were unlike himself in that they

were unaware of vaccines in Alberta's schedule. Javen's comment that some family physicians lack awareness that the province provides these vaccines further implied that he knew more than these physicians, and that all physicians should have some idea of the vaccines included in Alberta's routine schedule.

Most accounts of other professionals included bland descriptions of working with (and at times, around) professionals who were unsupportive of some vaccines. Aslia explained the need to work with those who held diverse beliefs about vaccines and how incomplete information can confuse the issue of vaccine safety:

I've met other allied health nurses, physiotherapists, or occupational therapists; definitely have met some that don't believe in vaccines. And [...] honestly, I don't think about it too much because when they're your colleagues you don't want to disrespect them, and this of course is their personal choice. I guess in some ways I just think that they don't have all the knowledge that they think they do. You know, sometimes you get a little bit of a knowledge and it ends up hurting rather than benefitting you, that's sort of the way, I guess the way I think about that (Aalia).

Aalia explained, she maintained collegial relationships with health professionals despite their disagreement about vaccines. Her statement that some information can be worse than no information positioned these colleagues as more ignorant than uninformed patients. Moreover, this statement allowed Aalia to present herself as well informed in comparison to colleagues who had the "little bit of knowledge," that could harm rather than help their understanding of vaccines.

Other interviewees reported that they were less accepting of health professionals who opposed immunizations—some interviewees expressed immense frustrations. One Public Health nurse exasperated that she had come across the occasional physician who advised against different newer vaccines:

MaKenna: Generally, physicians are pretty supportive for vaccination, but you do hear the odd one that holds a certain belief towards a certain vaccine, and it's usually the newer vaccines that are being released that they might say to their patient that they don't recommend it or it's probably not necessary or something. We've had that once or twice, and it wasn't a physician from this town, but another town and, yeah, it was just a newer vaccine and I'm not sure what the reasoning behind their beliefs were but . . .

TM: [...] can you give me some examples of newer vaccines?

MaKenna: Well the HPV is probably one of the newer vaccines and chickenpox hasn't been around as long as the other ones either so, or varicella. So when those vaccines come out there's the odd physician that isn't on board right away, but generally they're very good and supportive of vaccines.

MaKenna and other nurses stated that, unlike nurses, physicians were entitled to share their opinions with patients—including opinions that contradicted the vaccine narrative. As such, their accounts of their profession presented nurses' uncertainties as only vaguely relevant to patient counselling unlike physicians, which they would attempt to counter if they encountered patients who believed statements that countered the vaccine narrative.

In more extreme cases, especially regarding the measles vaccine, interviewees knew of colleagues who had similar concerns as some anti-vaccine proponents. For example, Johanna explained that a friend of hers had four autistic children and who believed that their autism was linked to the measles vaccine:

Yeah, I have a family physician friend, a lady with four kids, all four of them autistic. One was doing well until after he got his vaccination--he had speech delay shortly after. So she strongly believes that it's linked to them, so— and I can't convince her [...] (Johanna).

Johanna had vaccinated her children for measles and spoke of that vaccine's safety and efficacy, despite her ambivalence regarding the flu vaccine (which I mentioned above). Nonetheless, she voiced ambivalence about whether to provide her sons the HPV vaccine because the Alberta

government only provided that vaccine to girls at the time of the interview. As such, she was unsure whether boys benefitted much from that vaccine. She presented her ambivalence as a reasonable in contrast to links between autism and vaccination.

Another Public Health nurse explained how a physician had recommended against the rotavirus vaccine. Her account reviewed her frustrations of how other health professionals can impede her efforts to ensure immunity. Tori, who is a public health nurse, expressed immense frustration against a physician who recommended against the rotavirus vaccine:

Tori: [...] We'll have pediatricians say, 'Oh your baby doesn't need a rotavirus vaccine' right? Or 'They don't need the flu vaccine,' we're just 'Why? Why would a physician say that? What are they crazy? Like, why would you? Why?!' So, it's a huge source of frustration. And really, I'm supposed to find out who that health professional is and I'm supposed to report it to our clinical educator. And, she's supposed to follow up with that physician and, you know, sometimes we do and sometimes we don't. It depends if we have the information available to us and yeah...

TM: Does that come up a lot?

Tori: [...] Yeah, just today I had someone today who had a pediatrician—which is actually quite unusual in Calgary for a healthy child to have a pediatrician—and the pediatrician said the child did not need rotavirus. And the family went off to Hawaii for a holiday the child had rotavirus. They spent ten days in a hospital in Hawaii and it's just like, [...] it's not part of the publicly funded program, but you know they acted directly on his advice....

TM: Yeah. And when travelling it's—

Tori: Well, we hope to be giving rotavirus soon, like, rotavirus is a risk in the community. But, you know, I just think why? Why would you? Why, right? I don't understand. So just it's a level of frustration, right? [...] I really feel for parents because they're [...] taking the advice of the professionals that are in front of them and they're trying to do their best and it's a pretty hard situation for them too I know that.

Rotavirus fits within the category of "newer vaccines" because, as with the influenza vaccine,
Tori stated that these physicians believed that research into its efficacy is underway. In fact,
while writing this dissertation, I attended a family medicine conference (The Annual Scientific
Assembly: Education for Family Docs by Family Docs) at which there was a poster presentation
outlining an investigation into the efficacy of the rotavirus vaccine. Tori presented herself as
situated between physicians who can share their professional opinions and patients who may find
it difficult to navigate the plethora of perspectives that claim to provide reliable health
information. Tori accounted for physicians' questions into efficacy as dangerous when shared
with patients. She accounted for professionals who recommended against the vaccine as
"reportable," and thereby, as "others." She presented herself as a professional who upheld her
role mandated in the government guidelines that assume professionals support vaccines.

Furthermore, Adel, who is an urban family physician, mentioned a physician who had reservations about all vaccines. She provided an account of this physician's beliefs as unreasonable in comparison to her scientifically-based understanding of how the human body reproduces T cells:

I do know one physician who, who thinks, in summary, that they've got a limited amount of T cells<sup>58</sup> in your body and that the more you immunize the more you use up the T cellss, so you won't have enough to fight off infectious diseases as you get older as you've been immunized more (Adel).

In this account, Adel provided me with evidence that some physicians have formed unique understandings of vaccines and human biology. Again, I found no research to support claims that vaccines could deplete a body's T cell supply. This account situated Adel as more knowledgeable than the physician who she presented as holding erroneous beliefs about T cells.

<sup>&</sup>lt;sup>58</sup> T cells are "one of the primary cells of the adaptive immune response." Once mature, T cells are developed to protect against specific antigens (Venes and Taber, 2009).

Accounts of others' uncertainties contextualized professionals' accounts of the self in relation to colleagues who they presented to be less knowledgeable. Unlike their accounts of patients, accounts of colleagues positioned health professionals as knowledgeable beyond some of those in their practice. In a few instances, interviewees presented others' ambivalence as somewhat reasonable, given their personal circumstances (e.g., having autistic children).

Nonetheless, these accounts of uncertain professionals asserted the narrator's knowledge in relation to others who know less. Furthermore, although some interviewees shared their own uncertainties about specific vaccines, none attributed vaccine refusals to their own counseling. They explained that vaccine refusals resulted from patients' research and other health professionals' counseling. Professionals accounted for their own role in patient counselling as either effective, or in some cases uncertain because they did not know whether their patients received vaccines following counselling. They presented poor counselling, therefore, as that which intentionally guided patients to refuse or delay vaccination.

#### Conclusion

Every account is a somewhat fictional endeavour aimed at providing another with a convincing presentation of the self. In this case, accounts were situated within a wider culture rift with vaccine gossip, rumours, scientific talk, and narratives. That is, interviewees' accounts were situated within regimes of truth regarding medical discourse, common narratives associated with providing an account, as well as social norms, the limitations of memories, and the confines of language (see Butler, 2005). The accounts that interviewees offered from their position between medical discourse and public vernaculars offered persuasive evidence of their professionalism and the legitimacy of their profession. These accounts personalized and contextualized "objective" medical knowledge and the illusion of certainty, which are often used in professional

practice alongside subjective knowledge. Indeed, interviewees often interpreted medical knowledge through their own subjective, professional, or personal experiences.

In accounts about the boundaries of knowledge, interviewees presented their questions and skepticism of vaccines as evidence of professional qualities. These qualities included thoughtfulness, questioning influences on their practice (such as the role of the pharmaceutical industry), and the innate uncertainty that accompanies any medical procedure. Many accounts of the other, however, highlighted other professionals' and patients' uncertainties as evidence of a lack of understanding and knowledge. In doing so, the health professionals whom I interviewed demonstrated their own professionalism at the expense of the other. As such, they spoke of having better informed opinions of vaccination than some of their colleagues—albeit, at times informed through the personal experience of deciding whether to vaccinate their own children.

Primarily I analyzed these accounts in relation to narratives. Narratives apply scripted meanings to vaccines and to one's relationship to vaccines (Heller, 2008). Other forms of vernacular descriptions, such as scientific talk, gossip, and legend (Kitta, 2012: 28) were woven into some of these accounts. Similar to an account of the self, these other discourses and vernaculars (including scientific talk) around vaccines are rife with constraints from language, norms, and other social influences. The similarities in accounts predominantly emerged as "small stories" or "stock images," which reflected speakers' experiences from similar professional training, as well as social and political positions (Andrews 2002: 11; Maynes et al., 2008: 136).

Accounts of oneself include narrations of experiences, which include more than a simple iteration of facts and which are always presented in ways that are culturally, contextually, and historically specific (Roberts, 2002: 57; Smith and Watson, 2010: 31). The content in every account was a subjective effort to present professionalism, thoughtfulness, and contextually

important personal traits. Indeed, "an account of a person's life as seen by them [sic] at that moment" (Plummer, 1983: 57). Every account in this dissertation could have been said otherwise, or could have differed depending on the context of the interview, who conducted the interview, or the time at which it occurred. For example, those who accounted for their own changing opinions may have shared different accounts if I were to have interviewed them years earlier. Similarly, many interviewees may have changed their understandings of why patients or other professionals have uncertainties about vaccines. Indeed, there is no such thing as one "true" account (Butler, 2005: 38). The subjects providing the account constantly wrestle with how to most accurately represent their subjectivities within the confines of a regime of truth, the limitations of language, and the boundaries of their self-knowledge (Butler, 2005: 39, 42).

Interviewees provided accounts of their professionalism, which presented their own role, the boundaries in their knowledge, and their practice within a broader context of health professions and public opinion. These professionals practiced in Alberta, where they were expected to be purveyors of information to the less-informed public (see Alberta Health, 2007; PHAC, 2006a). Nonetheless, their accounts demonstrated some inconsistencies between their role as information providers and their thoughtfulness about the boundaries of their medical knowledge. Although I have not observed any encounters with patients, it is likely that professionals' awareness of their uncertainties could impact how they talk with patients about vaccines. Particularly, interviewees demonstrated that even health professionals may fill gaps in their knowledge about vaccines with outside information in ways that create some diversity amongst professional opinions (see Kitta, 2012). As such, professionals' accounts hinted at their social position amid diverse perspectives regarding vaccines and their professional and ethical responsibility to assist patients who are seeking reliable information.

## **Chapter Seven**

# "if you look at the impact that Jenny McCarthy had:" Risk, fear, and vaccination Introduction

During my Master's coursework, the movie, *I am Legend* came out. This film hyperbolized widespread fears of the measles vaccine and of pharmaceuticals to explain a fictional apocalypse:

What happens when you manipulate the measles vaccine into a retrovirus, then apply it to cancer patients in a clinical trial? In *Legend*, you cure cancer. At first. Then, the patients begin to get sick. Most of them bleed out, but those who don't become hairless, transparent, vampire-like mutants who are allergic to sunlight and crave blood. They spread the disease by biting others. When the virus mutates and goes airborne, it spreads rapidly, killing everyone on Earth except for those who are immune—and slowly, even they are picked off by the vampires, until only one man is left (Erin McCarthy, 2007).

A family physician whom I interviewed explained that anti-vaccine discourses were so pervasive that Hollywood utilizes them when producing fiction: "I know that there's lots of movies out there talking about turning patients into zombies" (Milan).<sup>59</sup> The stories in Hollywood only offer a taste of those that circulate through public discourses. In this chapter, I discuss how health professionals perceived the role of patient fears and narratives of vaccine risk regarding vaccine uptake.

Vaccine anxieties are pervasive with both vaccine sceptics who distrust medicine and supporters who fear disease. Furthermore, fear and other emotions are woven into medical practice and history: "The history of medicine has to be something more than just a history of

<sup>&</sup>lt;sup>59</sup> Conversely, other apocalyptic movies also provide examples of attempts to stop the demise of humankind through vaccines. The month before I defended my candidacy, *World War Z* became a box office hit. In *World War Z*, actor Brad Pitt's character helped find a vaccine that prevented the spread of the zombie virus. Regardless of which presentation of vaccines was more prevalent in Hollywood movies, it was clear which had stuck in Dr. Milan's mind when he called antivaccine discourses in movies "Hollywood nonsense."

knowledge; it also has to be a history of emotion" (Wootton, 2006: 22). Nonetheless, many people disregard emotions as belonging to medicine's past or to various alternative treatments. Health professionals' experiences with patients' vaccine fears and risk offer a vantage point from which to observe the role of emotion in their understandings of their roles, patients' anxieties, and the navigation of perceived risks.

Despite the prevalence of anti-vaccine discourses, little public dissent exists from the conception that vaccinations are good (Heller, 2008: 11). Jacob Heller (2008: 3) asserted that vaccination in the United States is at an all-time high: "The simple explanation for vaccines' continued public support is that vaccination works; the technical knowledge has been transformed into lay knowledge, something people can grasp without the baggage of scientific jargon and data. (This is also, in important ways, part of the narrative of vaccines: science works and deserves our trust)" (Heller, 2008: 9). Even so, the minute risks associated with vaccination may be difficult for many to grasp.

Indeed, much academic inquiry about vaccine fears and perceived risks targeted the antivaccination discourses that appear throughout public discourses, personal conversations, and especially, in online forums (Bean, 2011: 1875). Many vaccine supporters have purported that these discourses constitute an anti-vaccine "movement," which "causes" parents to perceive vaccines as risky (Blume, 2006: 634). Nonetheless, some scholars have found that most parents have concerns that differ from anti-vaccine proponents and hold views that support mainstream medicine, rather than alternative views about health (Blume, 2006: 635; Leach and Fairhead, 2007). For instance, Stuart Blume (2006) claimed that the number of parents who support antivaccine beliefs is too low to significantly impact vaccine uptake rates, and therefore, other issues have impacted vaccine uptake. He found that health professionals often provide information that

attempts to induce parental compliance rather than to inform patients (Blume, 2006: 637). He asserted that rather than apply the term "movement" to those who vocalize the risks of vaccines, particularly "the anti-vaccine movement," researchers need to examine broader issues that result in vaccine non-compliance, fears, and the perception of risk (Blume, 2006: 638).

Emotions and narratives shape perceived vaccine risks, uncertainties, and understandings of science. Health professions are positioned to help avert the statistical risks of disease and death by guiding bodies towards vaccine compliance and health (Foucault, 2004: 199). In doing so, health professionals respond to changes in their professions, which include individuals taking on increasing personal responsibility for their health (Fries, 2008: 353).<sup>60</sup> The professionals whom I interviewed often echoed these aims by stating that they worked against public narratives of risk to ensure that patients and the public remained healthy through compliance with vaccine schedules. That said, with the complex sets of institutions that offer definitions of "health," subjects have become "free to shop around" for what they think to be in their own best interests (Fries, 2008: 354).

Over recent decades, the state power that backs healthcare has increasingly incorporated patient choice, individualism, and consumerism (Blume, 2017; Fries, 2008). These changes also help perpetuate capitalist interests. These changes have accompanied changes in medicine about informing patients and gaining consent, meaning that: "Hierarchical, authority-led paternalism is

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<sup>&</sup>lt;sup>60</sup> Patient autonomy expands medical influence by "enabling the autonomous individual at the centrepiece of neoliberal governance" rather than by forcing actions (Fries, 2008: 354). That is, individuals become responsible to ensure that they function as "healthy and viable subjects for the state" by governing their own activities, including medical decisions, such as whether to vaccinate (Fries, 2008: 354). In terms of most of Canada's vaccination policies, individuals are expected to assess their options, and conclude on the best decision for their own health, based on their personal understandings. This type of healthcare model is based on assumptions that individuals will make health choices that are best for themselves and their communities. Some of the uptake rates necessary for herd immunity would require that *all* individuals who lack medical exemption from vaccination to be vaccinated (i.e., the measles vaccine).

giving way to discursive strategies of collaborative, patient-centred practice" (Bleakly, 2003: 186). Such changes are desirable to empower patients in most situations, but also problematic, given a plethora of questionable health advice and heavily marketed pharmaceutical products.

In what follows, I discuss how health professionals accounted for the role that numerous actors and competing narratives played in their efforts to persuade sceptical patients of the safety of vaccination. This chapter particularly focuses on health professionals' perceptions of patients' fears of vaccination. I analyzed professionals' narratives about patient fears in relation to theories that other scholars have used to explain perceptions of risk.

# Public health, fear, and vaccination safety

Pro-vaccine narratives and anti-vaccine narratives often aim to evoke fear. For instance, physician and author, Paul Offit, wrote several books about vaccines, alternative health treatments, and religiously based healthcare decisions. He used emotions, such as fear, to draw readers into his compelling arguments about the necessity and safety of vaccination. Offit (2011) began *Deadly Choices: How the Anti-Vaccine Movement Threatens Us All* with a narrative about the spread of haemophilus influenza type b (Hib [p. xi]). Drawing on emotions can create a compelling narrative, which encourages readers to fear the consequences of vaccine refusals. Alternatively, concerned parents argued that vaccines had harmed their children, which encourages other parents to fear vaccines. For example, the prevalence of vaccine fears resulted in compensation for families for health issues that were likely unrelated to vaccination.

Particularly, he cited the no-fault Vaccine Injury Compensation Program (VICP) and media representations of pseudo-scientific anti-vaccination information (Offit, 2011: 174-177). The VICP compensated parents for children's health problems that correlated with their vaccination dates regardless of causation (Glassner, 1999: 175-176; Offit, 2011: 21-22).

These narratives embrace widespread political and cultural techniques of using fear in ways that Glassner (1999) says ground opinion and public policy. In short, Glassner (1999) argues that public policy constantly negotiates with widespread fears and conceptions of risk, which means that policies cannot be wholly separated from emotion.

Narratives about risk have transformed since widespread fears about early vaccines, but they continue to articulate various *what ifs* and projections in ways that demonstrate "the persistence of fear in American culture" (Glassner, 1999: 177). Scholars who research risk know of such uses of fear. People have attributed various risks to different vaccines in relation to their historical and cultural contexts. These perceptions of risk are persistent despite ongoing medical advances.

Popular fears and narratives regarding the risks associated with immunization began with inoculations, which pre-existed vaccines, and transformed throughout their history. Early fears of smallpox vaccines and inoculations included death, the possibility of smallpox outbreaks, and impossible risks—such as the idea that vaccines could turn people into cows or turn white children into black children (Bliss, 1990: 48; Offit, 2011: 114-115). In the eighteen and nineteenth centuries, the possibilities of harm from the cowpox vaccination and its predecessors had yet to be scientifically calculated (Wootton, 2006: 155). Although immunization lacked scientific understanding at the time, many people, including many health professionals, considered the cowpox vaccination to be considerably effective (Ogbogu, 2014: 41).

Early in medicine's history, such fears of medical treatments are understandable. Immense risks were prevalent with many medical practices of the time, which had yet to incorporate germ theory and abandon such harmful treatments as bloodletting (Wootton, 2006). Many practitioners resisted incorporating safer and/or more effective treatments into their practices because of

emotional attachments to dated understandings of effective healthcare (Wootton, 2006). Moreover, physicians took a paternalistic approach to patient care, in which they expected patient compliance with treatments that often failed to improve health.

In Foucault's lecture series, *Security, Territory, Population*, he reviewed how relations of power guided vaccination policy in ways that aimed to protect the population from the risk of smallpox. In this series, Foucault's (2007) acknowledgement of pastoral power resonates with public fears and anti-vaccine revolts. With pastoral power, the medical professional is akin to a shepherd whose duty is to guide the entire flock to health (or away from risk [p. 199]). In this way, medicine and public health worked to secure the population in that they exercise power and encourage discipline by promising life. But, Foucault explained that this model gives rise to:

revolts of conduct, what we would call a strong medical *dissent*, from the end of the eighteenth century and still today, which extends [from] the refusal of certain medications and certain preventive measures like vaccination, to the refusal of a certain type of medical rationality: an attempt to constitute sorts of medical heresies around practices of medication using electricity, magnetism, herbs, and traditional medicine (Foucault, 2004: 199).

Foucault (2004) recognized that vaccine refusals could constitute a refusal of medical rationality. Even so, those who refuse vaccines but support medical knowledge face conflicting information sources and experience uncertainty about which treatments are based in rationality (Blume, 2006). As such, some "revolts of conduct" may be based in distrust in medical knowledge and/or awareness of the role of medical uncertainty. Such revolts could involve interpretations of medical knowledge that are filtered through narrative and emotion.

Some people who support rational procedures, such as vaccination, assume the refusal of rationality to be senseless or emotional. Indeed, emotions, particularly fear, often are contrasted with rationality when people avoid actions that are grounded in scientific evidence. Nonetheless,

many people who support vaccination demonstrate emotional understandings of the scientific risks association with declining vaccine uptake. As such, some health professionals and other supporters also rely upon emotions and narrative to express knowledge.

#### Risk and vaccination

Scholars have disputed whether parents focus on risks, uncertainties, or anti-vaccination claims. Some scholars treat risk and uncertainty as overlapping or identical. Rachel Casiday (2007) argued that parents conduct their own evaluations of the costs and benefits of vaccination in relation to their own families (p. 1061). That is, parents negotiate what they perceive to be competing anxieties when making decisions on behalf of dependents. These negotiations include both perceptions of risks, uncertainties, and benefits for the public and their own children, but parents evaluate things differently than quantifiable scientific studies (Casiday, 2007: 1061).

Casiday (2007) overviewed the limitations that accompany three streams of risk theory that scholars commonly used to discuss vaccines. First, Douglas and Wildavsky (1982) attributed risks to the social construction that occurs within different cultural groups. They articulated that the expansion of scientific knowledge often accompanies an expansion of uncertainty (Douglas and Wildavsky, 1982: 63). Moreover, they detailed that risk perception occurs as social phenomena, which include "moral ideals" about "the good life" (Douglas and Wildavsky, 1982: 80-81). They highlighted the importance of recognizing the social context within which risks are interpreted. Nonetheless, Casiday (2007) argued that this perspective involves the tautological assignment of those who perceive similar risks to similar "cultural" groups and that it lacks scientific evidence.

Second, in *Risk Society*, Ulrich Beck (1992) stated that risk entered public consciousness as a consequence of modernity. Beck (1992) argued that with modernity, people are increasingly

sceptical of the safety of various ecological, medical, and industrial influences on their bodies and surrounding environments (see Beck, 1992). Beck (1992) attributed risk to people's economic decisions and constructed a fairly monolithic "public" in opposition to a similarly uniform sector of scientific experts (Casiday, 2007). This attribution, however, fails to explain how vaccines are perceived to be risky in so-called "pre-industrial" countries and it inadequately addresses differences within the public and debates between experts (Casiday, 2007: 1063; Leach and Fairhead, 2002: 22).

Third, psychometric theories attempt to explain why lay conceptions of risk often oppose "expert" quantitative calculations. For example, Cass Sunstein (2002) discussed how government agencies attempt to conduct CBA of various regulations and policies in ways that are often haphazard, politically motivated, or inconclusive. Psychometric theories assume that individuals subjectively define risks and weigh the acceptability of different risks in ways that fail to account for interactions between culture, people, and politics; as well as how parents, health providers, and policy makers make decisions about children's health (Casiday, 2007). Lastly, CBA and risk society only explain risks in parts of the world that are similar to where they were written (i.e., North America and Europe).

I sample from these theories to explain how health professionals presented popular conceptions of vaccine risks and uncertainties. In particular, I build upon understandings of the role of narrative and emotion in patient understandings of vaccines.

### Risk, misinformation, and fear in cultural narratives

Much of the existent literature about vaccine uptake and refusal mentions narratives in passing, and occasionally in detail. Most literature, however, emphasizes the role of narratives from patients' perspectives of risk or the content of narratives (see Heller, 2008; Kitta, 2014;

Poltorak, Leach, Fairhead, and Cassell, 2005). I analyzed narratives from health professionals' perspectives of patients and parents' beliefs, rationality, and fears. I found that narratives and emotions emerged as topics during interviews despite my not asking specifically about those issues. That is, many of the health professionals I interviewed seemed to deviate from the "narrow risk-based framings" that previous research found Public Health Departments advocated (Poltorak, Leach, Fairhead, and Cassell, 2005: 711).

Immunize Canada and Alberta Health provide parents and health providers with information about vaccines with which they are to make individual decisions. Public health vaccine policies tend to promote education and free choice. For instance, Leach and Fairhead (2007) found that the United Kingdom's Department of Health encourages parents and health professionals to make decisions based on educational information that they provide (p. 49). Although many risk theories fail to explain vaccine anxieties as a global problem, the education and stories that parents and health professionals work with have implications for the global containment of disease and they vary depending on their local context. Leach and Fairhead (2007) argued that vaccination is a global health problem, but found that most risk theories inadequately represent various parts of the world.

Likewise, although some physicians had worked in other countries, most presented anti-vaccination as a problem only in countries that have nearly eradicated disease, where the population appeared to be ungrateful and ignorant of how vaccines had made the risk of disease invisible. Only Maya, an urban family physician specified the kinds of fears that manifest in other places:

Well I think there's some differences as I told you in [another country] many people were concerned about, like, the infertility. Our kids might become infertile, you know? And

here it's different so there are people who say it causes autism, [...] it causes developmental problems. So, it's quite different.

Indeed, Maya understood these differences as culturally based fears of a medical procedure.

Vaccine related fears manifested into different perceived risks that made sense within the existing cultural narratives (see Douglas and Wildavasky, 1982; Leach and Fairhead, 2007). The stories that emerged during most interviews illustrate the role of narrative in the interpretation of vaccines that is specific to Alberta.

Interviewees appeared aware that patients accessed much of their health information from outside sources, including celebrity statements. Indeed, Kitta (2014) found that the public rely on the retold and transforming stories that emerge from word of mouth, the media, and the internet as secondary sources to the information they gather from health professionals (p. 27). They expected emotion to be at the center of vaccination decision making and demonstrated desires to frame their perspectives of vaccines in ways that I found to be emotionally intelligible.

One public health nurse in an urban center explained her efforts to convince parents of the importance of preventative health measures in general:

If you're talking to a family that they've never seen a child have pertussis [...] So, it's pretty hard to say—Well, that's not a good example because that vaccine has very few side effects—But, it's pretty hard to say, "[...] There's a one in a million chance of an immediate allergic reaction, but ok there's much higher risk of pertussis." So yeah, that's very hard to communicate because your child isn't sick when I see them, so that's pretty hard to say. The whole preventive thing right? [...] You should eat well to prevent illness down the road. You should have vaccine to prevent illness down the road. It's a concept that's hard for people right, just living in the moment more (Tori).

Tori's account of counseling parents involved appealing to their perceptions of risk and their understanding of what is in their child(ren)'s best interest.

Likewise, a family physician explained that patients return for ongoing and repetitive counseling to quell their fears of vaccines:

Oh yeah, like I almost was late for this meeting and I still have a lot of work to do because I spent half-an-hour with this patient. [....] And they booked me off early, right. Always takes lots of time. Lots of time. It's a, and sometimes it feels like a big waste because you persuade, some people just never seem to be persuaded. But I think I have to be patient too. And because they're so afraid they come back again and again. They do. To ask the same questions over and over. They have to be told it many times. And they come because they're so afraid (Kian).

Kian's stories about discussing vaccines with patients centred upon appeals to both emotions and rationality. In fact, Kian was the only interviewee who informed me that he would challenge religiously-based vaccine refusals by asking patients to explain their religious objections. When patients failed to explain their objections, Kian took the opportunity to encourage them to think about differences between culture, tradition, and religion. As a result, he claimed some patients accepted vaccination.

As such, health professionals act as "agents of the state" who assist patients' attempts to navigate of perceived risks, and guide them towards the normalized decision to accept vaccination. As I discuss in the remainder of this chapter, health professionals are acutely aware that their efforts to guide patients' decisions occur alongside context specific vaccine stories, refusals, and uncertainties (Leach and Fairhead, 2007). In particular, interviewees critiqued the role of the media and prominent anti-vaccinators who they argued promoted the vaccine fears that their patients expressed.

# Let's all hate Jenny McCarthy

Jenny McCarthy and Andrew Wakefield emerged as infamous narrators of these stories.

Wakefield was a physician who lost his medical license for publishing an erroneous and

fraudulent study that linked the MMR vaccine and autism (Alaszewski, 2011; Godlee, Smith, and Marcovitch, 2011). Critics of Jenny McCarthy often highlight her history as a Playboy model even though she is also an actress, author, and activist (PBS, 2015). In an interview from 2010, McCarthy discussed her experience with her son, Evan, who was diagnosed with autism at 2.5 years of age and her understanding of the role of the MMR vaccine in his condition. Over the years, she has claimed to support "safe" vaccines rather than to oppose vaccination. Nonetheless, her concerns about vaccines have involved issues that the medical community rejected years ago—especially the supposed link between autism and the vaccines that her son received (PBS, 2015). Nonetheless, public concerns have encouraged scientific researchers to repeatedly test the relationship between vaccines and spurious risks, such as autism.

Many health professionals spoke of vaccine refusals as emerging from exposure to problematic vaccine narratives in lieu of education. For instance, Tori expressed her frustration by stating her distaste for Jenny McCarthy: "I really despise her a lot." Similarly, Aalia, an urban family physician, explained that celebrity endorsements often damage public support of medical expertise:

I just don't think it has a place in popular media. [...] Oprah and Jenny McCarthy, they're not experts. And, they are not giving a well-balanced view or a good review of the evidence. So, unfortunately I think that celebrity endorsements are pretty detrimental. I mean if you look at the impact that Jenny McCarthy had on immunizations, I think it was Jennifer Lopez did something pro-vaccination [...]. One of her kids got pertussis or something, so she did a campaign and I don't think it had anywhere near the impact in a positive way that a negative endorsement has in the popular media.

<sup>&</sup>lt;sup>61</sup> Jennifer Lopez is among many celebrities who have publicly supported of vaccination. For example, she made a public service announcement in support of the adult pertussis vaccine in order to prevent parents from transmitting whooping cough to their children (Sanofi Pasteur, 2009).

Aalia problematized media presentations of vaccine issues as being two-sided. She talked about vaccines as though they were risk free because vaccination as the safest option. Statements such as Aalia's contribute to the reproduction of a cultural system in which medical knowledge is "taken for granted as the preferred way of knowing medical phenomena" (Atkinson, 1988: 28).

Similarly, Monica, a family physician, elaborated that the apparently two-sided narratives about vaccines hamper parents' ability to recognize quality research:

I think there's a lot of misinformation out there. I think [...] there's been a lot of celebrities like Jenny McCarthy [...] putting up blogs [...]. It seems like there's a debate as if there's a pro and a con, rather than if you really look at the research it's an overwhelming pro. I think it confuses patients about what they should do what's best for their children. The last thing they want to do is give their children a toxic substance and I think they're seeing this con side on the internet [....] It makes them kind of question what they should be doing.

Monica accounted for how patient fears emerge from widely available pseudo-science claims. She argued that confusion from these claims impacts health professionals' ability to persuade patients that vaccines are safe. Even the retraction of papers often has limited impact on the public dissemination of narratives. Similarly, I asked Mariam, a rural family physician, about erroneous studies, such as Wakefield's article. She said people still ask about MMR and autism, but they do not always know where they heard about the link or are unaware it was retracted.

Likewise, Chandra expanded these concerns about press coverage. She explained that the media's role was to sensationalize such issues and maximize sales:

My estimation of the media is that they really quite enjoy negative headlines. So, I think if things are scary or can be made to look scary, then I think that sells, and therefore, that's how they portray things. And I think that's problematic.

As such, McCarthy and other anti-vaccine proponents represented a plethora of questionable sources of vaccine information that can influence parental decisions about vaccines.

Health professionals critiqued the sources of the stories and information that patients gathered about vaccines. Jayne, a rural family physician, explained:

as doctors, we get our information from the studies in respected journals. [...] [W]e also rely heavily on publications by Alberta Health Services, and we [...] follow their guidelines. But patients generally get theirs' from other sources and so people tend to listen to what's going on in the media. So if there's a big scare about something, patients, they have scares. But they don't come to us with their concerns about vaccines. I feel they go to public health.

Indeed, Jayne stated that patients' scares directly reflected "other" illegitimate sources of information, such as the media. (She explained her role in providing vaccine advice as less significant than some physicians who claimed to provide a great deal of vaccine advice.)

All health professionals grounded their opinions of vaccines in what they portrayed as legitimate vaccine information. As such, they framed their own stories as legitimate and separated them from illegitimate anti-vaccine stories. Legitimate stories appeared to promote scientifically supported information, with socially desirable morals (vaccines are good). They denoted illegitimate stories as the opposite. They were low quality, lacked validity, and promoted socially undesirable outcomes that professionals deemed a threat to health. Stories with provaccine morals were usually presented as legitimate even if they were based in opinion or sourced from social networks, the media, and so forth.

# The invisibility of disease and "that personal story"

Patients are increasingly aware of the limitations of safety, and may question mundane procedures including vaccination. The public may also rely on lay understandings to interpret scientific information. Lindsay Prior (2003) cautioned that equating lay understandings with professional knowledge conflates belief with knowledge: "One may believe in unicorns, but it would be difficult to claim knowledge of them" (Prior, 2003: 40). Lay narratives and risk

assessments often evoke more emotional responses than statistics or scientific measurements (Sunstein, 2002: 32). For instance, discourses that justify fears of vaccines are prevalent beyond those that espouse fears of the possible resurgence of communicable diseases. Treatments, such as vaccination, involve minimal risk, which manifests as either blatant uncertainty, or much more commonly, with an illusion of certainty. Indeed, safety is always a matter of degree rather than an absolute (Sunstein, 2002). Narratives can highlight the limitations of safety and the existence of minute uncertainties through the promotion of lay understandings of scientific procedures.

Health professionals often explained that parents lack an effective means to interpret the dangers that they attempt to mitigate for their children. MaKenna, a rural Public Health nurse, described how Public Health refrained from using any tactics that could "scare" patients. She explained that Public Health differed from anti-vaccine proponents in this regard:

[T]here's been discussions: Should we show pictures of these diseases? Should we put you know personal blogs of people whose kids had meningitis and lost limbs because of it, but they really don't want people to make the decision based on fear. But yet, that's what anti-vaccinators are doing right? [...] Parents are scared that something is being injected into their child and it's going to harm them. But, we're not allowed to do the opposite even though that's the real threat.

At the end of her explanation, MaKenna stated that diseases are the "real threat." She positioned Public Health as a rational assessor of risks in contrast to the emotionally charged statements that parents encounter from other sources.

Likewise, Kellan, an urban paediatrician, explained that parents often weigh the risk of measles less favourably than the risk of vaccination. That is, risks that parents could attribute to the unpredictable chance that children could catch diseases appeared preferable to the perception that they could directly cause harm by having them vaccinated:

There's something that's so scary the notion that you have a healthy child and that they get taken away somehow. [...] That they withdraw or become disabled. I mean that's every parent's nightmare. So I think we're, like at an instinctual level, we all want to avoid that. And something like measles, maybe [...] the community is getting more aware. But until recently, it might as well have been smallpox, kind of like it's just sort of this historical thing that you never see.

Kellan stated that communicating risk to patients was problematic because of their emotional reaction to supposed dangers from vaccination. He emphasized the value of narratives that portray medical knowledge:

[K]nowing the evidence is necessary, but not sufficient. Just sort of rattling off statistics isn't necessarily persuasive. And it's sort of the power of that personal story and really being able to sort of acknowledge the other side, but without creating some equivalency.

[....] I think that's a tough sell—that there's such a compelling narrative around vaccine risk. And even if it's somewhat flawed, [...] you sort of acknowledge and respond to it.

In his account of counselling patients, Kellan centred emotion as a means through which to enable knowledge translation.

Indeed, Kellan mentioned that personal stories tend to influence patients and efforts to manage these stories require great care. He said even nurses, physicians, and those with scientific training were susceptible to personal stories, especially when those stories detailed harm someone's child. For instance, Kellan knew family physicians who had autistic children and who associated that condition with the MMR vaccine:

I mean even people that are knowledgeable and have a medical background at some level they know that it's a bit questionable—what you hear about the risk of vaccination. But, [...] they figure on one hand the risk somehow at least in their perception of these illnesses is very low and on the other hand they live with autism every day and that feels very real. So the trade-off for them, it's sort of being on the safe side and avoiding vaccination.

As such, Kellan presented suspicions of links between MMR and autism as understandable, but wrong. In doing so, he demonstrated how healthcare professionals might accept some of the widespread risk narratives about vaccines, especially if they have personal experiences with those proposed risks.

Many health professionals said that they used narrative to share vaccine information in a personal and emotional, format. They provided short anecdotal evidence and/or lengthy explanations of cases they witnessed in their practice or families. For example, Milan, a rural family physician, succinctly informed parents that "you just need to look at third world countries and that's the first thing they do to try to help their health is vaccinations." Indeed, Milan's statement about vaccines in other countries is short, but it communicated his perception that vaccinations are simple and necessary health procedures that are safe enough to require limited consideration prior to acceptance. (In addition, this narrative presented vaccine ambivalence as something that is common only to countries that have nearly eradicated disease.)

Similarly, Zarah, a family physician, explained how personal stories about disease risks were particularly convincing to patients who were uncertain about whether they wanted to get the Zostavax vaccine:

I just try to let them know that it is available so they can try to make their own decision if they want to. [....] So if they have something personal, somebody that they know or somebody in their family that's had [shingles], they're much more likely to actually have [Zostavax]. So if they can see something, that means something to them. Not just someone telling them well you should have this because a lot of times even reading about it, they probably think, "oh well it couldn't happen to me right?" That's usually how it is [...] they don't think it could happen to them, and even the latest thing with measles is—a lot of older people. People that I just know—not even through work—just people in the community that I just hear talking about it, it's like, "well, we all had it when we were kids, it's not that bad of a disease."

The closeness of disease stories to parents was influential in their perceived impact.

Professionals explained that knowing the person who experienced the disease was more convincing than knowing that a large number of people experienced the disease. The presented patients as being convinced through narratives of medical knowledge, which acknowledged the personal and emotional implications of vaccine decision making.

The health professionals who I interviewed acknowledged the inaccuracies in many personal stories about vaccine risks and detailed how they countered such narratives with explanations of medical science and scientifically supportable personal narratives. Poltorak and colleagues (2005) found that Public Health often relied upon accounts of vaccine risks that failed to match parental reflections on the risks associated with the MMR vaccine (p. 711). Some of the health professionals I interviewed relied on simplistic statements that the benefits of vaccination outweighed the risks, but many of them supported such statements with tangible narratives. A few professionals expressed hope that the recent resurgence of measles would make the risks of vaccine refusal more understandable to parents who may otherwise refuse to vaccinate their children. That is, they hoped that the recent resurgence of measles would create a relatable narrative about the ongoing risks of vaccination refusal.

Furthermore, professionals often referred to the source of information and vaccine stories as evidence for or against their legitimacy. Interviewees presented government policy and medical discourse as the most legitimate, some pharmaceutical research was questionable, and stories from popular culture were problematic. Nonetheless, some interviewees explained that the content of stories suggested legitimacy or illegitimacy. For example, most interviewees readily accepted personal stories about the importance of vaccines and the risks of disease.

Although those I interviewed predominantly supported vaccination, they expressed some inconsistencies and attributed most vaccine uncertainties to patients. Even so, any given culture (and any profession [see Abbott, 1988]) is rife with divisions, diversity, and sub-cultures. These divisions are prolific and become more extreme when one looks beyond my interviewees. For example, Andrew Wakefield's study, which fraudulently linked the MMR vaccine to autism, epitomized such divisions within the medical professions. Wakefield is not alone despite assumptions that health professionals hold relatively uniform beliefs about vaccines. Dr. Jay Gordon (American), Dr. Bruce Hoffman (Canadian), Dr. R. Mendelshon (Canadian), and Dr. Bob Sears (American) are among various other health professionals who are listed on antivaccine websites or who counter the scientifically based evidence supporting vaccines on their own websites (Ask Dr. Sears, 2015; Novella, 2008; Offit, 2011: 48-49, 92-94,175-177; Vaccine Protest, 2013). These vaccine-critical professionals specialize in non-vaccine related areas of medicine, but their expertise increases the public's perception that their accounts of vaccine risks are legitimate, and therefore, the likeliness that some members of the public would believe their erroneous beliefs as scientific knowledge (see Prior, 2003: 51-52). As such, those I interviewed could face greater obstacles counseling patients who read materials written by such professionals. Extreme views supporting vaccines exist as well, but are much more difficult to recognize because they are very similar to those that appear to be common sense, mainstream, or culturally dominant, which presents vaccines as safe and effective preventative treatments. For instance, one of the physicians I interviewed, Monica, refused to be audio-recorded because she said she claimed to voice extremely supportive views of childhood vaccinations. She explained that she felt strongly that all children needed to receive their routine childhood vaccinations although she also stated some doubt regarding the importance of other vaccines (i.e., the

influenza vaccine). Monica may hold beliefs that are somewhat extreme about childhood vaccination, but she could also be highly vocal and committed to mainstream understandings of vaccines.

The health professionals who I interviewed appeared to rely on personal stories as a means to evoke parents' emotional understandings of the risks that their decisions could pose to their children in a similar way to how those who caution about the dangers of vaccines evoke fears.

They appeared to use narrative so as to reclaim emotion in the name of science and health in their efforts to persuade patients of the safety of vaccination.

#### Conclusion

Despite the role of anti-vaccine organizations, parents rely on primary health providers as their leading information sources about vaccines (see Keane et al., 2005: 2489; Smailbegovic, Lang, and Bedford, 2003: 306). Moreover, the health professionals who I interviewed may have a greater impact on patients' beliefs than they realize. Keane and colleagues (2005) found that most parents in their study (97%) relied on physicians (excluding chiropractors) as a source information regarding vaccination (2489; see also Smailbegovic, Laing, and Bedford, 2003: 306). Even so, health professionals address patients and parents as "health consumers" who shop around for the treatments that they believe best suites them in a social context that emphasizes risk.

Physicians and nurses work to promote government policies, which seek to maintain public health. According to Cass Sunstein (2002), government agencies attempt to mitigate risks with policies based on Cost-Benefit Analysis (CBA). CBA involves attempts to minimize risks by assessing the magnitude of problems, considering the potential trade-off costs to regulation, and creating inexpensive and effective tools (Sunstein, 2002: 5). Financial cost influences

government decisions regarding which vaccines to cover, which are considered alongside the potential costs of not vaccinating (e.g., the costs of treating diseases). Nonetheless, Sunstein (2002) explained that risk assessment and regulation occur more haphazardly than most analyses of ruling powers assume. Some questions about vaccine guidelines could represent concern that the CBA backing certain vaccines is based on social influences, such as the increasing commitment to "natural immunity" that some of the nurses mentioned (i.e., Naomi) or fears of pharmaceutical manufacturers' interests that some physicians mentioned (i.e., Chandra or Kian).

Many vaccine supporters frame parents' and patients' perceptions of risks as a lack of knowledge or they focus on the emotional role of health decision making. Framing risk perceptions as emotional or irrational is a means to avoid acknowledging that these perceptions could emerge from a distrust or suspicion of medical knowledge (Leach and Fairhead, 2007: 4). Likewise, Sunstein (2002) cautioned that this public mistrust could *cause* risk in cases where over-regulation results in the avoidance of options that are later deemed to be safer than those in use. As such, he is concerned that the cascade of beliefs and risks associated with public distrust and disagreement amongst different academics and between the government and academics.<sup>62</sup>
Risk from mistrust is blatantly apparent when vaccine refusals result in disease outbreaks.

Moreover, Beck (1992) asserted that anxiety about risk had become a defining feature in modernity. Despite Casiday's (2007) critique that Beck inadequately addressed differences within the "monolithic 'public' and an opposing sector of scientific experts" (p. 1062), he briefly mentioned that perceptions of risks are also specific to each profession, and divided within

<sup>&</sup>lt;sup>62</sup> For instance, with genetically modified (GM) foods people are concerned about safety because they believe little is known about the long-term and chronic effects: "it was precisely the denial of inherent uncertainties, especially about long-term or chronic impacts of GM, that was directly related to a public mistrust of the technology" (Hobson-West, 2007: 211). Sunstein (2002) asserted that based on the information available in the early 2000s, the possibility exists that modified food is safer, more abundant, and more nutritious (p. 37).

professions and the public (Beck 1992: 157, 195). Furthermore, scientific results are increasingly publicly available through media reports. Beck (1992) found that many scientific investigations go unacknowledged until the media reports on them: "Suddenly, the result loses any trace of research for private consumption; it haunts thousands of minds and thus demands personal responsibility and public (counter-)statements" (p. 197). Therefore, while Beck (1992) pays limited attention to narrative, any risk evaluation remains incredibly political through the proliferation of various forms of narrative, which are likely to evoke emotional responses.

In part through narrative, some perceived risks become political problems because an emotional public demands government regulation for certain risks, while leaving others unacknowledged (Sunstein, 2002: 121). In general, the public is unaware of which risks are most likely to cause their death. For instance, "people significantly overestimated highly publicized causes of death, including tornadoes, cancer, botulism, and homicide. By contrast, they underestimated the number of deaths from stroke, asthma, emphysema, and diabetes" (Sunstein, 2002: 34). People tend to accept some risks and abhor others (Sunstein, 2002). For instance, some vaccine narratives encourage parents to abhor the nonexistent risk of autism from the measles vaccine and accept the risk of measles—which has killed more children historically than any other virus. Sunstein (2002) cautioned that expert and lay assessments of risk diverge because lay people lack "a well-informed cost-benefit lens" (p. 32).

Indeed, many people fail to understand the nuances in regulation and treatment, which make zero risk (absolute safety) an impossibility (Sunstein, 2002: 11). Griffiths and colleagues (2005) stated that we could only estimate whether a particular individual will benefit from preventative medical surveillance based on research and statistics (p. 1079). Evidence-based clinical practice involves using research, often statistical research, to avoid overly relying upon individual

professionals' knowledge base (Griffiths, et al., 2005: 1084). In addition, cultural norms, public health policies, and neoliberal values encourage parents, especially mothers, to make health decisions based in part on their perceptions of risk (Reich, 2014). Risk, uncertainty, and the limitations of patients' knowledge create the possibility for concerned people to create narratives about the origins of various ailments and injuries.

Many professionals and academics have argued that expressions of uncertainty about the risks and benefits of vaccines are rising partly because vaccines have greatly contained disease and narratives about the risks of disease have fallen silent (Kata, 2010: 1079; Streefland, Chowdhury, and Ramos-Jimenez, 1999: 1713). The risks of vaccine-preventable diseases may seem inconsequential to some parents who distrust pharmaceutical interventions. These parents may find that risks resulting from one's actions (vaccinating) that could result in harm to be more horrifying than the perceived risk of disease from inaction (not vaccinating).

With all treatments, as with vaccines, humans experience risk and regulation in ways that involve social, economic, physical, and moral considerations (Eborall and Will, 2011: 655; Phipps, et al., 2011: 286; see Chen, 2005: 49). Preventative health treatments rely on some identification with the risk associated with refusal (Eborall and Will, 2011: 655), which people can convey through narrative and personal experience. The public needs to believe the promise that the treatment will secure their lives, and they need to believe that compliance with policies, including vaccine schedules, are much safer than noncompliance.

## **Chapter Eight**

#### Conclusion

Within any given locality, contemporary vaccine anxieties reflect broader concerns, but vaccine anxieties have existed in a variety of forms around the world and throughout different historical periods (Bliss, 1990: 48; Leach and Fairhead, 2002; Offit, 2011: 114-115). In wealthy countries where vaccines have lessened the risks of disease, anxieties often focus on concerns about harming children's development (Leach and Fairhead, 2002). Despite the widespread acceptance of vaccination, vaccine narratives, risk perceptions, and anxieties circulate across national borders much like the diseases they prevent (see Heller, 2008). Many people learn and share their perspectives about vaccination through contemporary legends, personal stories, and other combinations of narrative (Kitta, 2012: 21). By analyzing the prevalent narratives about vaccination, which health professionals shared with me, I noticed common occurrences in personal representations of uncertainties, risk perceptions, accounts of professionalism, and presentations of the other.

## Medicine's greatest lifesaver

The personal narratives and accounts that interviewees shared with me were situated by surrounding norms, professional guidelines, and a specific socio-historical context that I discuss in Chapter Three. Narratives about vaccine anxieties have existed since Edward Jenner coined "vaccination" to mean injection with matter from cowpox, but the content of those narratives has transformed to reflect contemporary anxieties about medicine. Vaccines became increasingly effective and scientifically explainable over the course of their existence. As such, the culturally dominant vaccine narrative is one that explains their success, necessity, and efficacy in protecting human life (Heller, 2008). Even so, smaller counter narratives exist for all types of

vaccinations, in part because of awareness that some medical and pharmaceutical interventions have caused harm (Wootton, 2006).

The smallpox vaccine was the first effective immunization, but it was also medically inexplicable for over half a century. Vaccines are now easier to explain with medical science. In fact, the evidence backing the vaccine narrative is often taken for granted, as evidenced in my interviews with health professionals and the copious amounts of medical research that back vaccines.

# Safety is always "a matter of degree"

Over recent decades, efforts to ensure that people feel safe from risks to their health have been based largely in corporate marketing and the provision of pharmaceuticals (Light, 2010). Michel Foucault (2004) argued that efforts to vaccinate the population were based primarily in efforts to normalize bodies by preventing the spread of disease. In recent years, the public, some scholars, critics, and some of the health professionals I interviewed seemed suspicious of the role of pharmaceuticalization in efforts to secure the population from disease. It is only possible to estimate safety because limitations exist in the extent to which risks are researchable (Sunstein, 2002: 142-143). Furthermore, drugs are approved as safe based on the often-problematic information that the Food and Drug Administration used in its approval process (Light, 2010: 7). In Canada, the task of determining pharmaceutical safety falls to the Health Products and Food Branch of Health Canada. I address these issues in Chapter Four.

Despite the constant existence of some uncertainty, Gigerenzer (2003) found that many physicians speak as if they are certain of the outcomes of any given treatment. With vaccines, uncertainty is less prevalent than with most pharmaceuticals, but perceptions of risk remain influential.

The health professionals whom I interviewed identified some potential sources of vaccine risk. Most participants focused on the active refusal of vaccination, and stated that the risks of missing vaccines due to difficulty accessing them were minimal. Some highlighted potential issues with access, especially with adult vaccinations. When interviewees accounted for risks associated with access, often they focused on financial barriers, such as the cost of the HPV vaccine for those who were older than the province covered or the cost of the herpes zoster vaccine (Zostavax) for seniors. In addition, some interviewees identified government policies as impeding vaccine uptake or failing to offer adequate coverage. For instance, some wanted to be permitted to vaccinate younger children against the flu when they vaccinated their families or to provide older patients with their tetanus updates during regular check-ups, both of which were not permitted under government guidelines.

Other professionals questioned whether the pharmaceutical industry influenced which vaccines the government approved for use in ways that aligned with scholarly concerns about pharmaceuticalization (see Williams, Gabe, and Davis, 2008). Several interviewees emphasized that ensuring patients use necessary pharmaceuticals as safely as possible was *part* of their job. By doing so, they separated their practice from pharmaceutical interests, which enabled some of them to critique pharmaceuticals and others to acknowledge the limitations of medical knowledge without compromising their professional presentation. Some of the critiques that interviewees offered aligned with those from patients and occasionally vaccine sceptics. For instance, one physician questioned the possibility that the measles vaccine could cause arthritis in rare instances.<sup>63</sup> Other interviewees questioned whether the number of immunizations was

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<sup>&</sup>lt;sup>63</sup> Some medical researchers have concluded that a possible association between measles and rheumatoid arthritis exists (Liu et al., 2013; Rosenau and Schur, 2009).

growing beyond necessity.<sup>64</sup> Moreover, some interviewees stated that certain vaccines were "newer," and therefore, they alleged that the risks associated with those vaccines were still in the process of coming to light. Although interviewees identified these potential risks and uncertainties, only some of them waivered in their support of vaccination, and they waivered only with specific vaccines.

#### Doubtless uncertainties

Throughout this dissertation, I used the term *uncertainties* broadly so as to include any gaps in a professional's personal knowledge, limitations in medical science, and any doubts that could emerge in relation to those uncertainties (see Fox, 2000). When interviewees expressed uncertainties, most included statements that I argue (in Chapter Five) helped them manage their uncertainties. They acted without the *doubt* that can accompany uncertainties regarding medical treatments that have less predictable outcomes than vaccines. Interviewees presented most instances of doubt regarding vaccination as something that others experience. Even so, some interviewees expressed uncertainties regarding specific vaccines, such as the influenza or varicella vaccines.

The management of some uncertainties is common to daily medical practice and patient encounters (see Knight and Mattick, 2006; Schattner, 2009: 76). Most of the physicians and nurses I interviewed were uncertain about at least some of the scientific details about vaccination or of some of their patients' vaccination histories. Overall, interviews included evidence of various tactics that appeared to prevent doubt from becoming an issue in health professionals' support of the dominant vaccine narrative. Specifically, interviewees used their own stories about

<sup>&</sup>lt;sup>64</sup> Interviewees concerns differed from research about vaccine-sceptical parents. Parents are more likely to perceive risk from providing too many vaccines despite scientific studies that have suggest no association exists between vaccination rates and the health problems that concern them most, such as developmental disabilities (see Offit et al., 2002; Smith and Woods, 2010).

the benefits and risks of vaccination, and they expressed trust in authoritative and expert knowledge about vaccines. These tactics were necessary because of the limitations of what an individual can know, unpredictable differences between patients' bodies, and the need to avoid overstepping one's area of expertise (Knight and Mattick, 2006: 1085; Prior, 2003).

# Professionalism and Accounts of Oneself

Arguably, all the health professionals I interviewed avoided overstepping their professional expertise. Most remained within their scope of practice by admitting they cannot know everything. In Chapter Six, I detailed how they explained how their personal uncertainties were evidence of professionalism and they seemed to accept their role as an advocate for vaccination.

When stating their uncertainties, health professionals provided accounts of their role from a social position that was between vaccination experts and the wider public. In doing so, they provided what Judith Butler (2005) called an *account of oneself*, during which they attempted to persuade me of their professionalism and thoughtfulness. Accounts are always incomplete and somewhat fictionalized because they emerge from human memory, within a given social context, and are bound by the limitations of language (Butler, 2005: 37-42). Interviewees provided accounts of the boundaries of their own knowledge, but all reasoned that they knew all they needed in order to care for their patients.

Many health professionals accounted for their own uncertainties about specific vaccines as though they evidenced thoughtfulness. In contrast, they accounted for other professionals and sceptical patients as others who embellished risks because of spurious reasoning or being misinformed. Identifying others as responsible for vaccine refusals and low vaccine uptake rates meant ignoring wider issues in medicine, offsetting the blame from the individual professional,

and placing it onto other individuals. As such, they accounted for their own professionalism at the expense of others, who they presented as less informed.

## Others, media, and misinformation

In Chapter Seven, I review how health professionals' accounts often referred to the role of media and gossip when they described the sources of misinformation. In these accounts, health professionals acknowledged that patients often were emotional, and that patients' decisions to refuse vaccination could be influenced by fear. They acknowledged a myriad of sources including news media, Hollywood movies, and social media. Despite these sources, health professionals accounted for their own uncertainties as if they emerged from legitimate and accurate sources. Even when listing uncertainties about specific vaccines, they expressed support for the dominant vaccine narrative by stating that vaccination, as a general concept, was the safest option for themselves as well as patients. Finally, although health professionals often argued against patients' use of subjective personal stories, often they relied upon narratives that complimented vaccination policies to explain why vaccines are valuable. As such, health professionals appeared to be aware that vaccination compliance requires some identification with the risks of vaccine refusal, and, they attempted to explain those risks in easily understandable personal narratives.

In all likelihood, the professionals I interviewed primarily saw patients who have access to vaccines and who vaccinate. As such, it is unsurprising that they see these problems as emerging from a minority of misinformed individuals and as resolvable through educational initiatives.

Even so, they identified types of patients as unwilling to vaccinate, and at times, they listed other health professionals who were uninformed. In doing so, they emphasized parental choice over

vaccine uptake and maintained the necessity of individual action in the navigation of population risks.

#### Limitations

As with my participants' accounts of self, I expect that this account of my research includes some shortcomings that I have overlooked. That said, I identify a few that I believe could be addressed in future research. This project focused strongly on the context of Alberta, where a strong emphasis exists on free choice in health decision-making. At a time that I collected my data, the province was experiencing relatively high income levels with relatively fewer disease outbreaks than many parts of the world (Alberta Treasury, 2013b: 1; Alberta Treasury, 2013c: 2; PHAC, 2006b). Diseases, however, spread beyond provincial and national borders. As such, incomplete vaccination delivery is a global problem that requires ongoing international attention. Understanding local contexts helps with responding to immunization anxieties, which vary in different communities (Leach and Fairhead, 2007).

Moreover, the health professionals who participated in my study may have been motivated to do so because of their own perceptions of vaccination and uncertainties. Because of participants' interest, this dissertation includes talk about both childhood and adult immunizations.

Throughout the course of this project, it became clear that more research is needed for the provision and distribution of adult and senior vaccines. Many interviewees seemed eager to discuss their interpretations of their patients' concerns—some included concerns regarding access to vaccination. If I had a different information sheet or title, then they may have brought up other issues.

<sup>65</sup> A few non-participants mentioned the importance of adult vaccination when they declined to participate, and some interviewees brought up the issue as well.

Finally, this study focused on health professionals' experiences. While I believe that understanding health professionals' perspectives is important to understanding healthcare, a future step would be to interpret these concerns in relation to patient concerns and observations of professionals' discussions of vaccination with patients. Observing discussions would be difficult because many professionals acknowledged that these conversations can happen unexpectedly when patients ask questions during routine visits.

#### Health professionals' narratives, vaccines, and medical uncertainty

In relation to their own understandings, interviewees' narratives often emphasized what they perceived to be patients' experiences, opinions, and needs. That is, many of my interviewees appeared hopeful that research (possibly my research) could help improve vaccine uptake rates or help them navigate some of the uncertainty and nuances that are central to daily practice (see Gerrity, Green, and Bendelow, 1999; Fox, 2012; Knight and Mattick, 2006). This dissertation explored several topics that appear to be under-represented in existent literature.

First, the existence of uncertainties in even mundane procedures is currently underresearched. Despite the safety of vaccination, many Albertans may perceive it to be an
unnecessary treatment because it is provided to healthy children in communities, which for the
most part, experience few disease outbreaks. Some interviewees mentioned speaking with
parents and patients who were aware that safety is always a matter of degree and, while often
they demand certainty, the denial of all uncertainty could magnify perceptions of risk. Some of
the health professionals whom I interviewed addressed the existence of trivial safety concerns by
stating that patients are savvy to the limitations of medical science, and that their understanding
needs to be acknowledged. Indeed, although the health professionals whom I interviewed had

some vaccine uncertainties, often they accepted uncertainty as inherent to the medical practice and maintained support of vaccination with minimal doubt.

Second, Alberta's vaccination program focuses on the role and expertise of Public Health nurses. Most of the professionals whom I interviewed are responsible for individual patients, and primarily, for issues other than vaccination. Even when providing vaccination advice, their concerns rest with individual health, rather than population health. My findings demonstrate that Albertan physicians' opinions of vaccination vary somewhat. Even though individuals likely receive a great deal of information from Public Health nurses, they could receive variable information from physicians whose opinions they may deeply respect.

Finally, although my sample was relatively small and likely biased (given the number of health professionals practicing in Alberta), I believe that it demonstrates the necessity of ongoing professional development. Health professionals expressed variation in their perspectives about vaccines and the training that they received. It is unreasonable to expect professionals to hold identical views, but the diversity of views I observed, including those that interviewees claimed have changed, could have resulted in part from the acceptance of inaccurate vaccine information regarding a few vaccines. Most interviewees stated that vaccines were underemphasized in their educational programs.

Rationalizing away emotional responses to perceived health risks and decisions about children is impossible. Similar to vaccine information, widespread vaccine anxieties often take a narrative form (Heller, 2008; Kitta, 2014). Narratives about vaccine anxieties are culturally and historically situated (Leach and Fairhead, 2007; Poltorak et al., 2005). Furthermore, health professionals are situated between vaccine experts and the public. In fact, many health professionals, who should be better educated than the public about vaccines, express some

uncertainties or ambivalence about specific vaccines (Bazylevych, 2011; Dubé et al., 2011; Levi, 2007; Loulergue et al., 2009). Despite their attributions of others' narratives to irrationalities, health professionals often relied upon personal narratives as evidence of their own knowledge and authority.

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#### **APPENDIX A: Recruitment Letter**



# Medical Knowledge and Uncertainty: Healthcare Professionals' Narratives of Childhood Vaccines

You are invited to participate in a study, which seeks to understand healthcare professionals' experiences advising patients about childhood vaccines. I have worked in the Department of Family Medicine for three years as a research assistant, and I am conducting this study as my dissertation research in the Department of Sociology.

Interviews should last up to thirty minutes, depending on your availability, and I am happy to provide lunch if you would like a lunch meeting.

Please contact me for further information and scheduling:

Phone: 780-231-6689

Email: tmanca@ualberta.ca

Thank you for your consideration!

Terra Manca PhD Candidate, Department of Sociology Research Assistant, Department of Family Medicine University of Alberta

#### **APPENDIX B: Consent Form**

# Medical Knowledge and Uncertainty: Health Professionals Narratives of Childhood Vaccines

<u>Principal investigator</u>: Terra Manca (PhD Candidate in the Department of Sociology at the University of Alberta). Contact: **780-231-6689**; <u>tmanca@ualberta.ca</u>

<u>The Project</u>: Patients rely heavily on medical professionals, especially physicians, to address their growing concerns regarding childhood immunizations. Anti-vaccination discourses and uncertainties within the wider population have complicated interactions between patients and their physicians who provide immunization advice. These discourses and uncertainties are growing problems within medicine, and some high-profile physicians and alternative practitioners have publicly advised against specific vaccination practices.

In addition, research into the role of uncertainty and apprehension in the medical practice is increasing, but no research has investigated thoroughly issues regarding childhood vaccination. Some recent research, however, has demonstrated that even some advanced year medical residents hold diverse beliefs regarding vaccination. Uncertainties around vaccination may include medical knowledge around specific vaccines or types of patients, professionalism and soft skills, potential manufacturing or distribution errors, effectiveness of vaccines given declining uptake levels, or other related topics.

I am addressing these issues in my dissertation research through qualitative interviews with physicians about their professional experiences advising patients concerning immunization. The goal of this project is to understand physicians' vaccination practices in relation to popular conceptions of vaccines.

<u>Procedures</u>: At this stage, I am collecting personal and professional accounts of the challenges, successes, and uncertainties involved in advising about childhood vaccination. Although I will have some questions to ask you, the interviews are semi-structured—meaning that you may provide your account in your own words. **Interviews should last about thirty minutes**, but may be longer or shorter depending on your engagement with the topics and your availability. With your permission, I will audio-record the interviews.

<u>Possible Benefits and Risks</u>: This project will provide data about the successes and challenges that physicians experience when advising patients regarding preventative treatments for children, which could be beneficial for other physicians' lifelong learning or for medical residency programs. Moreover, it could provide additional findings, such as evidence of how knowledge operates in medicine, the difficulties of remaining up-to-date with medical research, and so forth. Risks associated with this project are minimal to nonexistent, but might include any potential stress you may feel around the research topic.

<u>Confidentiality and Voluntary Participation</u>: I will keep confidential all of the information from the interviews and I will encrypt the transcripts into electronic files. Anonymous excerpts from transcripts may appear in such scholarly work as articles, lectures, presentations, and my dissertation. After completing each transcription, I will exclude names and identifying information from all material. Only I, Terra Manca, (and my supervisor, Stephen Kent, PhD) may view confidential information.

Any information that you share or withhold will have no impact on your career. You are free to refuse to answer questions or withdraw your consent at any point during or after the interviews.

<u>Research Ethics Approval</u>: A Health Research Ethics Board at the University of Alberta has reviewed the plan for this study for its adherence to ethical guidelines. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

<u>Contact information</u>: I am scheduling interviews now; and I hope to be able to schedule one with you. If you would like more information or would consider participating in this project, then please contact me. I will do everything possible to accommodate scheduling or time restraints. If you would like to contact my supervisor (Dr. Kent), then his contact information is below.

Terra Manca (principal investigator) tmanca@ualberta.ca 780-231-6689

Dr. Stephen Kent (sociology professor) steve.kent@ualberta.ca 780-492-2204

Thank you for considering this research project, I look forward to hearing from you.

### **Consent Statement**

I have read the information sheet associated with the research project "Vaccination, Medical Knowledge, Practice, and Uncertainty." Terra Manca answered any questions that I had regarding this study and I know I can contact her or Dr. Stephen Kent with future concerns. I am free to withdraw from this study at any time or refuse to answer any questions without explanation. I have a copy of the information sheet and will receive a copy of this information sheet and consent form upon signing it.

Participant's Name (printed) and Signature	Date
Name (printed) and Signature of Person Obtaining Consent	Date
Optional:	

☐ I would like Terra Manca to contact me so that I may access her research findings upon completion of her dissertation (expected in 2015).

#### **APPENDIX C: Interview Guide**

- 1. Background
  - a. Approximate age
  - b. Experience practicing medicine: How long have you been practicing? Where have you practiced? Do you have residents or students?
  - c. Education: Where did you complete medical school? When did you finish? Any specializations?
  - d. Children and young adults in practice?

#### Vaccines in AB:

- 2. What do you think is the biggest issue with vaccines in Alberta? Canada? General? What do you like about Alberta's vaccine program?
  - a. Do you think AB's vaccine goals are reasonable?
  - b. What do you think about uptake levels?
  - c. Other issues?
- 3. Have you encountered other issues with vaccines in other places you have practiced?
- 4. Given that there are constant updates in medical knowledge, vaccines are constantly changing composition, and manufacturers change; how do you assess the necessity and safety of the current vaccine regimens?
  - a. How do you stay up to date with current vaccine developments?

# Knowledge and Training:

- 5. How has your knowledge of vaccines changed since you began practicing? Why?
- 6. How do you feel about your knowledge and professional training regarding vaccines? Why? What training did you have? Do you believe your residency program provided adequate information? Other residency programs?
- 7. How do you recognize quality research into new vaccine risks? (i.e. Wakefield before he was disproven).
- 8. Are you confident in your knowledge around vaccines?
  - a. Are there any particular vaccines that you are more or less confident about? What do you think is the basis of your confidence (i.e. medical knowledge, ability to explain risks, importance, or safety?)
  - b. Are there any specific children or ailments that you think could pose unforeseen risks with vaccination? Seizures related to vaccines in child or family (immunization guide says to vaccinated with precaution in future); other adverse reactions?
- 9. How has your confidence regarding your knowledge of vaccines changed over time?
- 10. Do you have colleagues who hold different beliefs regarding vaccines than you do?
  - a. Have you ever heard colleagues discuss uncertainty about vaccines? Any residents?
  - b. Do you work with other health professionals who hold different beliefs around vaccines than you do?
- 11. Have you received all recommended vaccines?
  - a. Have your children received all recommended vaccines?
- 12. Personal and/or professional experiences with communicable diseases?
  - a. Advising about Vaccines
- 13. How important to do you view your role in advising about immunization?

- 14. Do you ever experience apprehensions about advising patients to follow any recommended vaccine schedules?
  - a. Competing Moralities: Philosophical, Religious, alternative medicine (I.e. Some adults hold objections to such vaccines as the HPV vaccine because it offers young women protection against a sexually transmitted disease.)
  - b. Time: Is time an obstacle to discussing vaccines? Do you allocate more time to certain vaccine concerns than others?
  - c. Memory: Is it easy to remember to address vaccines in appointments?
  - d. Other: Demanding patients, Potential litigation or complaints from patients, etc.
- 15. Are you confident when advising parents about vaccine safety?
  - a. How do you know your counseling will be effective?
  - b. Do you have to deal with patient uncertainty? How do you do this?
  - c. At what point do you begin advising parents about vaccines?
- 16. Have you ever seen significant vaccine side effects? (i.e. seizures, anaphylactic reactions, or etc.)
  - a. Would these side effects influence how you advise about vaccines?
- 17. Do you have any parents who refuse to vaccinate or request changes to the vaccine schedule?
  - a. Do you believe it is safe to adjust vaccine schedules in response to parents' concerns?
- 18. What are your thoughts on popular representations of vaccines? (popular includes internet sources, news, television, socializing, blogs, etc.)
  - a. Do popular representations of vaccines impact your practice?
  - b. How do you navigate these popular representations?
- 19. Do you support any alternative medicines? Do you have thoughts about the use of alternatives to vaccines, such as homeopathic nosodes?
- 20. Some physicians describe religiously-based refusals to be particularly difficult to discuss with patients. Does religion ever influence the vaccine information that you provide? Events:
  - 21. Do you have any thoughts about the measles outbreak in Southern Alberta?
    - a. Any factors influencing vaccination rates? Anything physicians could do?
    - b. How safe do you think it is for parents to refuse the measles vaccine for their children?
    - c. Are there any circumstances in which you view vaccine refusal to be child neglect? Do you know what the limit would be to the types of medical refusals you respect?
  - 22. Did you hear about supposed links between the old H1N1 vaccine and narcolepsy?
    - a. Recent stories about sleeping sickness in children suggest that Pandemerix ASO3 adjuvant and Canada's H1N1 vaccine with adjuvant from GSK. Physicians on CTV hypothesized that the vaccine caused narcolepsy in some children who were predisposed to the disease and those physicians are currently conducting research.
  - 23. Changes to the HPV vaccine to include males? Was it sufficient when only females?
  - 24. The flu vaccine has emerged as an area that some health professionals disagree about. Do you believe the flu vaccine is effective for children? Is it useful for children?

# **APPENDIX D: Immunization Schedule at Time of Study**

Age	Vaccine
2 months	DTaP-IPV-Hib
	Pneumococcal conjugate (PCV13)
	Meningococcal conjugate (Men C)
4 months	DTaP-IPV-Hib
	Pneumococcal conjugate (PCV13)
	Meningococcal conjugate (Men C)
6 months	DTaP-IPV-Hib
	Pneumococcal conjugate (PCV13; for high risk children only)
6 months and older	Influenza
12 months	MMRV
	Meningococcal conjugate (Men C)
	Pneumococcal conjugate (PCV13)
18 months	DTaP-IPV-Hib
4–6 years	DTaP-IPV
	MMRV
	Pneumococcal conjugate (PCV13) only for children up to 71 months
	(catch up program)
Grade 5	Hepatitis B (3 doses)
	HPV (3 doses for females)
Grade 9	DTaP
	MCV4

<sup>\*</sup>This table is based on the immunization schedule in the *Alberta Immunization Strategy* (Alberta Health, 2007: 5).

### **APPENDIX E: Methodological Reflection**

# Vaccines, my perspectives, and my academic experiences

My interest in vaccines began with questions about the limits of child medical neglect and parental responsibility. For instance, Gordon Francis was a former Christian Scientist whom I interviewed him for my Master's thesis. It was clear that Francis's parents had avoided vaccines:

They [my parents] never would turn to medical care. And there was, you know, if I had some kind of treatable disease, I still would go without treatment, as I did. You know, I had measles and mumps and chickenpox, none of which I was treated for, and so I'm lucky that I'm healthy.

Francis questioned his parents' decisions regarding their children's health:

We have medical science, which as imperfect as it may be, saves lives. We have physicians, who as imperfect as they may be are trained [...], and they practice a real science. And you know, to not avail yourself of that as an adult is one thing, but to not avail of your children who are sick is irresponsible. And you know, any belief system that would have a parent make such a decision is an irresponsible belief system (Gordon Francis, interviewed 2008).

During his interview, Francis clarified that he would have preferred vaccination to the childhood illnesses he had suffered. My interview with Francis, my research about Christian Science healthcare decisions, and the other topics I have investigated, spurred my questions about vaccination.

Before this project, topics that sparked my interest involved social worlds that seemed removed from anything I experience day-to-day. Writing about family and health issues in New Religious Movements offered me some insulation from analyzing the borders of what I perceive to be medically necessary treatment.<sup>66</sup> Specifically, I have found it easy to critique refusals of

<sup>&</sup>lt;sup>66</sup> Likewise, I had challenged myself similarly by interviewing current Christian Scientists for my master's research rather than relying on solely former members' accounts as I have for many

such medically necessary treatments as diabetic insulin or blood transfusions for children. My stance on immunization was always less certain. I feel strongly about the necessity of childhood immunizations to protect individuals and the population, but I understand that "safe" implies minute risks (in that safety is a matter of degree rather than an absolute). Moreover, mandatory immunization is problematic, but voluntary adherence to any immunization schedule requires the normalization or normation of the population (I discuss this in Chapter Three; see Foucault, 2004: 57).

It is unclear how likely unvaccinated children are to contract a vaccine-preventable disease, let alone spread that disease. The risks of refusing a vaccine are incalculable. Unlike medical treatments that heal childhood ailments, I was uncertain about questions of communal and parental responsibilities regarding vaccines. (Should vaccines be mandatory? Are parents whose children suffer preventable disease, morbidity, or death mistreating their children? On what grounds could vaccine exemption be allowable, and for how many children?) As such, I approached my dissertation topic as an opportunity to challenge my preconceptions and theoretical understandings.

News stories and supposedly scientific evidence often highlight hypothetical dangers associated with vaccines. <sup>67</sup> Eventually, many of these alleged dangers are proven erroneous. For example, clinical investigations have disproven the purported link between the MMR vaccine and autism (see Poltorak et al., 2005: 710; Prior, 2003). Yet, some of these supposed dangers have appealed to highly intelligent and critical minds. For instance, I attended a course where a well-respected professor discussed the potential links between Gulf War Syndrome and the

of my other research projects.

<sup>&</sup>lt;sup>67</sup> Some academic studies have analyzed the prevalence of media that addresses vaccine uncertainties (see Bean, 2011; Hilton et al., 2010; Kata, 2010).

anthrax vaccine. The majority of contemporary North American vaccine refusers are well educated.

In fact, I am susceptible to such vaccine suspicions. Prior to this project, I found myself distrustful of newly manufactured vaccines, but my suspicions receded slowly. I had personally foregone the H1N1 vaccine during the 2009 outbreak, discussing it with a graduate student who had researched the anthrax vaccine. More recently, a controversy regarding narcolepsy and the H1N1 vaccine surprised me (see CTV, 2013; Picard, 2011). This controversy cited Pandemrix (a version of the H1N1 influenza vaccine issued in Europe), which was not used in the United States where adjuvanted influenza vaccines were not licensed, but it was used in Canada (CDC, 2013; CTV 2013). I found public narratives about such vaccine uncertainties to be extremely problematic. When I read through the back comments in the news article about H1N1 and narcolepsy, I found that the physician hypothesized that the vaccine had prevented many cases of narcolepsy that the wild virus would have caused (CTV, 2013). Uncertainties, such as this potential link, demonstrate that even vaccine supportive individuals, including healthcare professionals, could have some uncertainties.

In 2013, I received my first flu vaccine (predictably, without any notable adverse effects). The reasons I had previously forgone this vaccine were unclear to me, aside from my awareness that previously there was a fee associated with the injection. The government of Alberta removed the fee that young healthy Alberta healthcare cardholders paid for this vaccine in 2009 (Government of Alberta, 2014). As the daughter of a family physician and researcher who is suspicious of medical refusals, my own noncompliance with this vaccine is something that I continue to piece together. Yes, I perceived the threat of the flu virus to me to be low, but I also

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<sup>&</sup>lt;sup>68</sup> Adjuvanted vaccines are those that include a compound to "increase the body's immunological response" to an antigen (Venes and Taber, 2009).

believed that protecting those at risk from the virus was integral. Yes, my ex-husband, who actively opposed immunization, likely influenced me, but he remained uninvolved in my healthcare choices. Furthermore, I disliked the idea of waiting in a line to receive a vaccine, which may have been the largest factor in my noncompliance. In any case, I selected a research topic that I thought could change my own behaviours and beliefs; a topic that I hoped would refine my understanding of other medical issues even if it left me less certain of my own theoretical perspective.