IS IT WORTH THE SHOT? ONTARIO WOMEN'S NEGOTIATIONS OF RISK, GENDER AND THE HUMAN PAPILLOMAVIRUS (HPV) VACCINE

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ABSTRACT

This research project has been an endeavor in understanding how Human Papillomavirus (HPV) vaccine policy became gendered in Canada, how women in Ontario negotiated the concepts of "risk" and "gender" deployed in pharmaceutical marketing and public health programming, and how they folded these mediations into decision making about the vaccine. Eighteen months of ethnographic fieldwork revealed that the federal and Ontario governments developed HPV vaccine policy by using gender based analyses frames, based on the parameters of Merck Frosst's gender-based marketing. This case study of the HPV vaccine highlights how corporations and governments work hand and hand to set public health policy in the neoliberal era of public health. However, these sales/governance strategies and the gendered at-risk subject formation they created and circulated were not passively integrated by women into their daily lives. The women interviewed – mothers of daughters affected by the grade eight school vaccination program, women university students and patients at a hospital vaccine clinic – demonstrated that the concepts of "risk" and "gender" are productive and movable ontological modes of being, which shift in and out of focus depending upon the context. Mothers were intensely focused on gender and doing mothering, students were doing gender politics and intermittent risk, and patients were living with risk. What sales/governance strategies had tried to "fix," women continually unfixed. These accounts of situated risk and gender demonstrated that when assembled, women's experiences helped transform their ethical being or sense of self. This knowledge of the self then informed vaccination decisions. Thus, decision making was not a discrete event or a linear, cost-benefit analysis. Instead it was an inherently social and cultural process, which was embedded in women's experiences of finding meaning in their efforts to be good mothers, strong young women emerging into adulthood and pre-cancerous patients seeking respite amid the anxiety of protracted medical procedures. Women's ontological decision making provides an analytical framework through which to tie together risk- and gender-related theory, individual accounts of risk encounters and the social, political, historical and economic context in which these mediations occur.

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TABLE OF CONTENTS

Chapter One: Introduction - Research Focus and Scope

Chapter Two: The Introduction of the HPV Vaccine in Canada: Gender-Based Risk-Making

Chapter Three: Gathering Women's Narratives - Lived Experiences of Gender and Risk

Chapter Four: "To Vaccinate or Not to Vaccine?": Mothers Negotiating HPV Vaccination Decision Making for Daughters in School-based Immunization Programs

Chapter Five: “Let’s Talk About Sex” – Women University Students Share Their HPV and HPV Vaccine Stories

Chapter Six: Pre-Cancer Experiences – Containing HPV Through Negotiating Cervical Dysplasia Treatment and Opting to Vaccinate

Chapter Seven: Women’s Productive Re-Ordering of Risk and Gender and Ontological Decision Making

Chapter Eight: Conclusion - Contributions and Considerations for Moving Forward

LIST OF FIGURES

CHAPTER ONE – Introduction: Research Focus and Scope

Introduction: Setting the Ethnographic Stage

Generally an anthropological dissertation starts off with an illustrative anecdote. Such an anecdote serves a double purpose. It works to place the reader within the "thick" (Geertz 1983) of the ethnographic experience of the writer and metaphorically references the research project at hand. However, this dissertation cannot begin with one particular research-related vignette. Such an approach would be disingenuous and would reflect neither the research project goals nor the resulting analysis. Throughout the research project, the objective was to understand women's numerous and varied responses to medicalization and specifically the human papillomavirus (HPV) vaccine. As Lock and Farquhar note, "what has emerged from interest in the human body, as it is lived, is a multiplicity of bodies. . . . [T]hey cannot be summed up in any one kind of narrative" (2007:2). With this in mind, here are three snapshots of ethnographic encounters with interviewees who have left a lasting, post-fieldwork, impression on me.

First there was Carmen, a fellow mother and academic. During our interview, this poised and self-assured professor was a bit rattled. Besides being somewhat harried because it was back-to-school time, Carmen also faced the decision of whether or not to have her daughter vaccinated against HPV. Emily had entered grade eight and on the first day of school had brought home a large packet of forms to be signed that included everything from pizza ordering to school accident insurance requests. Also included was an HPV vaccine consent form. The consent form needed to be returned in four days in order for Emily to be eligible for the three-phased shots. The stress of the decision making process was visible on Carmen's face. Having the responsibility of making health decisions for someone else is a weighty proposition and Carmen was anxious and uncertain about her decision making. As she said, "It's a catch-22"; she was not facing a clear-cut, win-win decision. If she did not vaccinate her daughter and she developed cervical cancer, Carmen would never forgive herself. However, if she put Emily through an unnecessary vaccination experience and exposed her to vaccine side-effect risk, she also would not forgive herself.

Second there was Sylvana, a university student who persistently sought, for over six months, to arrange an interview with me so that she could share her HPV story. Sylvana was a health sciences major, frequent medical consumer and had experienced HPV infections. Sylvana could not come to a definitive decision whether or not to be vaccinated and wanted to be interviewed because she needed someone to talk to regarding her HPV experiences. The stigma associated with being a woman who had contracted a sexually transmitted infection (STI)[1] enforced a "culture of silence" around

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[1] Please note that medical and policy terms relating to HPV and the vaccine are explained in the glossary, which can be found in Appendix A.

HPV infection and this left her with limited social avenues through which to share her experiences.

Third there was Rebecca, a 40-year-old mother of one who had experienced HPV infection in the form of varying grades of cervical dysplasia or pre-cancer, for ten years and was now a patient at the hospital-based vaccine clinic. Because of her infections, she was subject to a slew of medical procedures, including everything from protracted Pap testing to colposcopies to LEEPs. Rebecca felt that it was not possible to prevent HPV infection, but only to "contain" (Douglas 2002[1966]) it. Rebecca was anxious about her pre-cancerous state and was skeptical as to whether or not the vaccine would stave off future infection of HPV strains she had not already been exposed to. Her motivation to get vaccinated stemmed directly from her stress-ridden experiences with cervical dysplasia. While there was no guarantee, Rebecca was willing to give the shot a try.

As these vignettes indicate, researching the HPV vaccine was an intense experience. This intensity was exacerbated by the topicality of the vaccine as an issue of public debate and concern. As a mother and graduate student, I moved in and out of communities in which the vaccine was discussed daily. The lines between the "field" and my personal time were porous. When I volunteered at a reading program for elementary school children at my children's school, other mothers wanted to know what I thought of the vaccine and even went so far as to ask me if they should get their daughters vaccinated. When asked this question, I tried to maintain a balanced approach by outlining the information that was circulating for and against vaccination. As I had two boys, I was never directly asked if I had my own children vaccinated. The issue of the vaccine was so timely that I should not have been surprised when one evening during fieldwork I attended a home-based yoga class and walked into an HPV kitchen vaccination. The mother of the household was taking a vial of the vaccine out of her fridge so that her neighbour, a nurse, could administer it to her teenage daughter. The vaccine, however, was not just a matter of discussion among the people I encountered daily, but dominated the mainstream media as well. It was not uncommon for newspapers at the time to frequently feature articles on the vaccine, or to wake up to stories about the vaccine when the morning alarm went off. Vaccine advertisements were also routinely visible on the subway and even made appearances during the Saturday morning cartoon hour. The “field” seemed to be everywhere.

As a result of this immersion in the vaccination “field,” this research project makes a marked departure from existing social science literature on the vaccine. Current literature addresses several topics: the vaccine and minority health within bounded groupings demarcated by ethnicity (see Fernandez et al. 2009; Lazcano-Ponce et al. 2001; Livingston et al. 2010; Luque et al. 2011, Lucque et al. 2010; Pitts et al. 2009); parental attitudes towards vaccination (see Chapman 2010; Das et al. 2010; Dempsey et al. 2006; Ogilvie et al. 2007); women’s knowledge concerning HPV and the vaccine (see Medieros and Ramada 2010; Pitts and Clarke 2002) which often pits women’s views against those of men; gay men and the vaccine (see Epstein 2010); health care provider attitudes towards the vaccine (see Mishra and Graham 2012); and the framing of the vaccine as a prophylactic measure against cancer and not as an STI prevention tool (see Braun and Phoun 2010; Mamo et al. 2010; Prescott 2010; Wailoo et al. 2010). While these topic areas vary, each study is narrow in scope as none are the result of long term fieldwork engagement. Nor do these studies offer a critical treatment of the concepts of "gender" and "risk." In short, existing research does not offer in-depth qualitative data concerning vaccine negotiation or provide adequate political, economic, historical and social contextualization to robustly understand and make sense of decision making.

In exploring the narratives of women like Carmen, Sylvana and Rebecca, this research project remedies these shortfalls by providing accounts of "situated risk" (Boholm 2003:158) and gender. In examining situated risk, anthropologists are able to move between three points: grand theory relating to risk; individual accounts of risk encounters; and the political, social, historical and economic context in which risk is produced and negotiated. Situated risk allows for the critical analysis of the "structural dimension[s]" that affect individual risk negotiation and provides textured ethnographic accounts of such mediation (Boholm 2003:158). This goes beyond existing research in other social science fields highlighting risk, which generally focuses on meta theory (see Beck and Willms 2004; Castel 1991; Dean 1999; Giddens 1991; Giroux 2010; Gordon 1991; Ewald 1991; Fox 1997; Petersen 1997; Rothstein 2006) *or* individual accounts (see Bond et al. 2012; Brown et al. 2013; Crighton et al. 2013; Gross and Shuval 2008; Lear 1995; Russell and Kelly 2011; Spencer 2013; Thing and Ottesen 2013; Tuinstra et al. 1998; Walls Dr et al. 2010; Zinn 2008). Concentrating solely on grand theory leaves out the important human element of risk, and only researching individual experiences reproduces risk-related governance strategies, albeit unintentionally. Highlighting individual accounts of risk without adequate contextualization reinforces the new public health's focus on individual self-regulation (Petersen 1997). However, as important as the situated risk concept is, it does not address how gender intersects with risk-related decision making, nor the specific governance techniques associated with gendered risk-making (Lupton 1999a; Moore 2010). As a result, this research project focuses on both situated risk and gender through the additional inclusion of theory from Allen (2008), Butler (2008), Douglas (1992, 2002[1966]), Lupton (1997a, 1997b), Moore (2010) and Nettleton (1996, 1997) in order to incorporate a feminist perspective into the analysis.

A] Research Agenda and Analytical Frames

In order to provide situated accounts of risk and gender, fieldwork occurred over an 18-month period and included multiple sites. Research began with three months of archival study to determine how HPV vaccine policy became gendered in Canada when the virus is gender blind and associated with cancer affecting individuals of all genders (Braun and Phoun 2010). The archival research tracked how the concepts of "gender" and "risk" were deployed in pharmaceutical and policy discourses vis-à-vis the HPV vaccine. This meant pouring over documentation which included Gardasil® advertising campaigns, popular media accounts, parliamentary debates, federal and provincial press releases, accounts of lobbying before the federal Finance Committee, and federal regulatory decisions regarding the vaccine. Critical discourse analysis of these sources revealed that messaging relied upon the overarching notion that women are a "feminine" (Bartky 1990, Moore 2010) grouping – a homogenous and static "whole" that is inherently at risk for ill health. Merck Frosst was the first to deploy this governance technique as a selling mechanism for the vaccine, but if this conceptualization of women had not been in the ether, it would not have been picked up again in the gendered policy making processes surrounding the vaccine. Thus, the marketing tactics and policy development surrounding the vaccine functioned tautologically as sales/governance strategies. This archival research provided baseline data on how "gender" and "risk" were deployed in these discursive knowledge nodes and I drew on it as I formulated interview schedules.

The next step in the research process was to understand how these concepts were received, amalgamated and refuted by women. This entailed interviewing three cohorts of women: mothers negotiating the vaccine for their daughters in a school-based immunization program, university students who were targets of HPV vaccine promotion in campus health clinics, and patients who attended a hospital-based HPV vaccine clinic. Interviews focused on how women negotiated the concepts of "risk" and "gender" in their daily lives vis-à-vis the vaccine. How did women make sense of and experience these concepts? What did these concepts mean to them? How did these experiences affect their vaccine decision making? In answering these questions, I examined the vicissitudes of power – how power was deployed and how it was processed. However, in order to avoid repeating the power techniques used in the sales/governance strategies of the pharmaceutical and governmental discourses surrounding the vaccine – i.e. assuming women occupy a static, whole and homogenous at-risk grouping – I paid close attention to the nuances and flexibility that women employed regarding risk and gender. I paid specific attention to the variability women applied to their mediations of risk and gender in their everyday lives.

To get at the heart of women's experiences of situated risk and gender, data analysis followed Foucault-inspired governmentality approaches to risk (Castel 1991; Giroux 2010; Gordon 1991; Lupton and Petersen 1996; Nettleton 1997; Petersen 1997; Rose 2007; Rothstein 2006; Turner 1997) *and* late Foucault theory (1987, 1989, 1990[1978], 1991, 1997, 1999). Foucault's governmentality writings are frequently taken to task for their predetermined nature (Sawicki 1991). However, once the spectrum of his writings is examined, the tightly woven governance strategies of the governmentality period are unraveled, ever so slightly, in his later work focusing on subjectivities. Foucault, if the full scope of his work is taken into account, acknowledges the construction of subjects within the frameworks of power relations, but also the possibility that such subjects are able to level their own limited "critiques" even though enmeshed in the webs of power

(Allen 2008:21). Women's narratives provided an intersubjective "space" where subject formation and realizations/actualizations of the self intersected. It was in this "space" that health negotiation and decision making occurred. Correspondingly, interviews provided moments of generative pause. Not only did interviews allow for contemplation, they were productive events. Mothers and students ruminated on and processed how HPV infection and HPV vaccine risk was being transmitted by governmental and pharmaceutical discourses and how they were hybridizing or rejecting these messages. However, women were communicating far more than an account of their vaccine decision making during interviews. When in the thick of a pause, each woman created a narrative that contributed to her continually developing sense of self that re-inscribed and re-enforced her identity. Women are not always portrayed as "doers," but throughout vaccine negotiation and decision making women worked towards becoming "ethical" beings: women who create their own "telos" or sets of codes for maneuvering daily life (Foucault 1997:265). Scripting one's telos is a temporary transfer of power and this reflects women's ability to be "self-constituting" (Butler 2008:2). Therefore, women enacting situated risk and gender demonstrated that risk could be harnessed and "practiced" (Zaloom 2004:368), a concept akin to Butler's treatment of gender.

Fieldwork data revealed that something quite specific took place when women spoke of their decisions whether or not to have their daughters or themselves vaccinated against HPV. Their ethical agency, in an overarching sense, involved aspects of Thompson's "ontological choreography" (2005). In the case of patients, and more tangentially students, ontological choreography was joined by the "biographical disruption" (Bury 1982) of being chronically ill. When ontological choreography and biographical disruption intersected, women consciously and pointedly engaged in re-ordering. Thus, the concepts of risk and gender were movable ontological modes – risk and gender moved in and out of focus depending on the context. For mothers, risk was a theoretical construct; their daughters were just moving into their teenage years and the last thing they wanted to do was explore adolescent sexuality with their daughters. HPV risk was for the mothers a distant proposition. As a result, mothers focused abundantly on gender and "doing mothering" (Glenn 1994). For students, HPV risk was intermittent as many had experienced transient HPV infections in the form of genital warts and the beginnings of low-grade cervical dysplasia. Students were also worried about long term vaccine side effects and were outraged at the gendering of HPV and the vaccine. Students based their vaccination decisions on the type of gendered being they wanted to be – one that was not put in a pre-determined, at-risk "box" (Douglas 2002[1966]:125, 172). Students were, therefore, dealing both with risk and gender in equal measure. The risk students experienced, however, was nothing like the risk patients were living with. Patients thought the risk was so all encompassing that there was no means by which to escape it, but only strategies through which they could contain it. Due to the intensity of risk for patients, which they recounted in their diagnostic and treatment narratives, gender took a backseat. Narratives across all three cohorts indicated that in relation to women's senses of self, risk and gender were elastic concepts. In response to the creation and circulation of a totalizing and static gendered and risky HPV-related subject – which attempts to keep women in order and prompts them to follow orders – women re-ordered *their* lives. This re-ordering also led women to take part in ontological decision making. Vaccine decision making was not the product of individual rational choice, but of social and cultural processes. Women's vaccine decisions were layered into, and a result of, their active and situated experiences with gender and risk. Their situated experiences of doing mothering, doing gender politics and intermittent risk, and doing risk detail, respectively, their efforts to be good mothers, strong young women emerging into adulthood, and pre-cancerous patients seeking a "pause" amid the anxiety of protracted medical procedures. Each of these states of being was directly linked to the vaccine decisions of the three cohorts: mothers' overwhelming decisions to have their daughters vaccinated, students' decisions not to be vaccinated with a small portion delaying making a decision, and patients' unanimous decisions to be vaccinated in an effort to take a step back from HPV infection.

Conclusion: Summary of Chapters

These analytical conclusions are the products of a long journey through fieldwork and participatory analyses. Before recounting this journey, a précis of the chapters to come – a brief sketch of the ethnography as it unfolded – is provided.

In chapter two, gender-based analyses (GBA) relating to the HPV vaccine, whether it is of gender-based pharmaceutical marketing approaches or governmental gender-based policy making in Canada, are examined, and the part these pharmaceutical and governmental frames play in constructing the girl/woman who is at-risk for cervical cancer are explored. This framing leverages hegemonic cultural logics concerning gender and risk, and functions as a sales/governance strategy that places girls/women in a pre-determined box removed from the sites of power. In order to keep girls/women in this box, the HPV vaccine is positioned as a cancer fighting mechanism. This side steps HPV as a sexually transmitted infection, and proffers a vast platform for sales/governance because cancer, as opposed to STIs, is culturally interpreted as wide reaching, mysterious, fear inducing and multi-causal. It is important to emphasize that GBA as applied in the case study of the HPV vaccine, treats gender as pertaining primarily to women. In this rendering, women are translated into an undifferentiated and static grouping – a grouping of tangible at-risk subjects. This chapter serves as a historical, economic and political contextualization to trace women's responses to this very subject formation.

Chapter three focuses on methodological approaches and experiences in the field. Once I completed the archival research, my goal was to find people, places and spaces where I could connect with women to unearth their experiences of the HPV vaccine. Securing an institutional arrangement – meaning a clinical space to conduct participant observation – was a challenge, but one that was arranged, albeit in a modified form. In addition, the enthusiastic response received from women regarding the research project, including the additional student cohort, was most unexpected. As such, I discovered on-the-ground HPV policy that had a clinical, as opposed to governmental, impetus, as well as the integral part that HPV infection stories played in HPV vaccine decision making for many women. It also became evident that findings could solicit strong and emotional responses from other academics in conference settings. Thus, tracing how women mediated the concepts of "gender" and "risk" within the confines of vaccine negotiation took on enriched dimensions that required fluid approaches to fieldwork.

While chapters two and three provide the theoretical and methodological foundations for the research project, the next chapters move into women's responses to the HPV vaccine. In chapter four, I explore mothers' narratives in regard to their vaccine decision making for their middle school-aged daughters. Mothers exhibited anxiety, strong emotions (both in terms of enthusiasm and disdain) and uncertainty regarding their HPV vaccine decision making. The weight of HPV vaccine decision making was exasperated by the relatively short period of time they had in which to make a decision.

Continuing along the theme of women's response to vaccine decision making, chapter five features women university students' experiences with HPV infection and vaccine decision making. This chapter is about students' HPV stories, as Sylvana so eloquently put it. Students called for widespread sexual health education of sexually transmitted infections (STIs), and specifically HPV. In interviews students off-loaded their anxieties of having contracted an STI and receiving very little social support. Students passionately discussed the gendering of HPV and the HPV vaccine, both through commercial advertising and within the governmental realm of current school-based vaccination programming in Ontario. This gendering was so off-putting to students, along with their concerns of potential vaccine side effects, that the majority of those interviewed decided not to get vaccinated or to delay vaccination.

In chapter six, patients at the hospital HPV vaccine clinic talked about their experiences with cervical dysplasia diagnoses, the resulting treatments and deliberations regarding the vaccine. Their sense of cancer risk had a different frame of reference than that of other women interviewed – they had been engaged with risk in the past, experienced risk in the present and were waiting to see if it would rear its head in the future. Patients with frequent cervical dysplasia presentations were suspended in a liminal, pre-cancerous state. They were at-risk for cancer, but knew this risk might never materialize, particularly if they underwent interventions to remove the pre-cancerous cells. Patients talked about how difficult it was to prevent HPV infection and instead looked to contain HPV. HPV vaccine decision making among patients rested squarely on their experiences with cervical dysplasia. This being said, however, patients had a tempered view of the vaccine and its effectiveness given their medical histories.

In chapter seven, the women's narratives of three cohorts are tied together through an exploration of the conjunctures and disjuntures of their lived experiences of situated risk and gender. This is where the central thesis of this dissertation is explained in full. There were indeed similarities among the cohorts – students and patients experienced widespread stigma for having contracted HPV infections. Mothers and students focused intensely on gender in the HPV vaccine debate and their vaccine decision making. All women had to mediate the “traffic” (Rapp 2000:185) between the at-risk gendered subject formation that HPV-related pharmaceutical and governmental discourses created and their own lived experiences of situated risk and gender. Women’s narratives indicated that the concepts of risk and gender were movable ontological modes of being. Narratives from all three cohorts demonstrated that in relation to women’s senses of self, risk and gender were elastic concepts. What sales/governance strategies tried to make concrete, women re-tooled by finding meanings in ways that governance strategies could not predict or control. Narratives also demonstrated that decisions regarding vaccination were ontologically driven. The identities women fashioned when re-ordering risk and gender were directly linked to vaccine uptake outcomes.

In the conclusion (chapter eight), findings are reiterated in order to establish the theoretical and pragmatic contributions this research project makes to the discipline of medical anthropology. The greatest impact this research project has is its ethnographic exploration of situated risk *and* gender. As Lupton (1999a) and Moore (2010) have so eloquently established, there is little existing research that explores the impact of risk on women and their bodies in a critical fashion. Current risk-oriented research that features women, although unintentionally, reproduces this gender as an undifferentiated grouping that requires intervention because of their “feminine” vulnerability. As such, gender norms are re-inscribed over and over in existing research. This research project, however, attempts to remediate this troubling trend by exploring the nuanced and layered fashion through which women negotiated risk and gender vis-à-vis the HPV vaccine. Women’s negotiations revealed complex on-the-ground re-ordering of gender and risk and the ontological basis for vaccine decision making. Throughout these negotiations women were engaged in generative pauses – moments in which their identities were constantly being re-worked and re-fashioned. Thus, what sales/governance strategies tried to fix, women continually un-fixed.

Before reading further, however, please be assured that the research and findings are not intended to evaluate scientific research and practices regarding HPV, the vaccine or cervical dysplasia interventions. Nor is this research project an attempt to judge women who are vaccinated against HPV. Instead, this is an endeavor to take a step back from a social science of medicine perspective, and analyze how sales/governance strategies organized women’s “individual realities” (Petryna 2002:119) and how women responded to this type of organization. I am very aware of the toll cancer takes on families as members of my immediate family have died of cancer, live with and are in remission from cancer. Throughout the fieldwork and the analysis of the resulting data, I have been ever mindful of individuals and families facing cancer; these experiences, while not an overt part of this research project, were nonetheless, never far from my consciousness.

CHAPTER TWO - The Introduction of the HPV Vaccine in Canada: Gender-Based Risk-Making

> Each culture has its own special risks and problems. To which particular bodily margins its beliefs attribute power depends on what situation the body is mirroring. It seems that our deepest fears and desires take expression with a kind of witty aptness. To understand bodily pollution we should try to argue back from the known dangers of society to the known selection of bodily themes and try to recognize what appositeness is there.
> [Douglas 2002(1966):150]

Introduction

In this chapter, gender-based analyses (GBA) relating to the HPV vaccine are examined – whether it is gender-based pharmaceutical marketing approaches or governmental gender-based policy-making in Canada. GBA have played a crucial role in constructing the girl/woman who is at-risk for cervical cancer. This scripting harnesses hegemonic cultural logics concerning gender and risk, and functions as a sales/governance mechanism, which places girls/women in a pre-determined box removed from the sites of power. In order to keep girls/women in this box, the HPV vaccine is positioned as a cancer fighting mechanism. This curious framing, which sidesteps HPV as a sexually transmitted infection, provides an expanded platform for sales/governance because cancer is culturally interpreted as far reaching, mysterious, fear inducing and multi-causal. It is important to emphasize that GBA related to the HPV vaccine treat the concept of gender as pertaining primarily to women. In this rendering, women are translated into an undifferentiated and static grouping – a group of tangible subjects. The aim of this chapter is to provide a historical, economic and political contextualization to the subject formation of the HPV-related girl/woman-at-risk and to provide the requisite background needed to trace how women respond to this subject formation.

A] The Governmental Roll Out of the HPV Vaccine

Mass media accounts generally describe the introduction of the HPV vaccine to Canada as a swift development (Gordon 2009, Gulli et al. 2007, Picard 2007). This is, however, not the case. In 2005, the Public Health Agency of Canada released a report entitled *Canadian Human Papillomavirus Vaccine Priorities Workshop*, (the workshop took place November 17-18 of that year). The aim of this workshop was to "examine the current Canadian and international status of HPV vaccine research and develop national research priorities before the vaccines become approved for use in Canada" (Public Health Agency of Canada 2005:iii). When referring to vaccines, the report referenced both Gardasil® and Cervarix®, but Gardasil® received approval in July of 2006 for girls/women whereas Cervarix® did not receive such approval until much later in February of 2010 (Notice of Decision for Gardasil®, Health Canada 2006; Picard 2010). At the outset, the workshop report discusses HPV as being connected to multiple genders, but most of the document's text positions HPV as a "woman's issue." This is selective framing as HPV presents in women, men, intersex and transgendered individuals and is linked to gender-specific and gender-blind cancers (Parkin and Bray 2006). Individuals with male sexual organs can develop penile cancer, and those with female genitalia can develop cervical, vaginal and vulvar cancers; any gender can develop oropharyngeal (throat) or anal cancer from HPV, as well as HPV-related genital warts and recurrent respiratory papillomatosis, which present as warts in the throat region (Centers for Disease Control and Prevention 2012). However, the Public Health Agency of Canada report emphasizes the utility of HPV vaccines in primarily preventing cervical cancer.

Attendees of the November workshop included senior federal bureaucrats, scientists, researchers, physicians and numerous representatives from Merck Frosst and GlaxoSmithKline Biologics (PHAC Workshop Report 2005:28-30). Thus, pharmaceutical companies were present “at-the-table,” even before Merck Frosst officially submitted its request for Health Canada approval of Gardasil® on December 12, 2005.[2] It could be argued that the presence of pharmaceutical companies at the governmental planning workshop is a conflict of interest, but their presence should not be surprising considering the current era of what the federal government calls “smart regulation” (Graham 2005:1469). Industry now plays a significant role in governmental regulation processes, from initial consultations regarding the introduction of a product to Canada to its regulatory approval and eventual roll out. Smart regulation was introduced in March 2005 and aims to “restructure Canada’s regulatory policy . . . [to]

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[2] Merck Frosst’s application was processed in seven months due to its application being given priority review status (Health Canada Summary of Basis Decision 2006).

streamline and speed up approval for new drugs, foods, biotechnology products, veterinary products and pesticides" (Graham 2005:1469). Smart regulation is geared, simultaneously, to expediting the integration of new business ventures into the Canadian marketplace and safeguarding the public interest through strong regulatory frameworks. Graham is skeptical that the government is able to meet these dual priorities and posits that business interests generally trump those of public health (2005). Within smart regulation frameworks, pharmaceutical companies pay user fees in order to have their drugs reviewed by Health Canada's Therapeutics Product Directorate (TPD). As Lexchin observes, "as funding for the operations of the TPD shifts from the government to the drug companies, a situation is created in which the drug companies could be perceived to be setting the priorities" (1999:173). User fees are a "cost-recovery" measure. For example, in 2004, 51 percent of TPD's budget came from user fees; the remaining was sourced from government monies (Silversides 2010). It is not surprising that Gardasil® received expedited approval from the TPD given this regulatory climate.

On February 15, 2007, the National Advisory Committee on Immunization (NACI) released a report on the HPV Vaccine. This was a crucial document in determining the roll out of the vaccine because NACI is charged with providing physician recommendations regarding who should be vaccinated and when, and how the vaccine should be administered. This document is exhaustive and references HPV infections in women and men, but primarily focuses on the linkage between HPV and cervical cancer. The NACI report was publicly released before the Health Canada Summary Basis of Decision on the vaccine was issued in March, 2007. A Summary Basis of Decision document provides the approval for a pharmaceutical to be used in Canada whereas NACI is charged with recommending how a vaccine should be utilized. Thus, the document providing the framework of how a vaccine should be administered was distributed before the vaccine was approved for use in Canada. Interestingly, the Summary Basis of Decision mentions that boys from nine to 15 had been included in Gardasil® clinical trials, but that research was ongoing in boys and men from 16 to 26 years of age (2007:17).

On March 27, 2007 the *Canadian Medical Association Journal* (*CMAJ*) published a "thought piece" in its news section called *Debate begins over public funding for HPV vaccine*. This is a balanced article that outlines the potential benefits of the vaccine and potential objections to a public inoculation campaign.[3] *CMAJ's* concerns center on the lack of long-term data on HPV vaccine immunity and the social uproar a publicly funded vaccination campaign for a sexually transmitted infection could cause. The piece also discusses vaccinating boys, but mentions that "publicly funded programs are not expected for several years" (Comeau 2007:913). *CMAJ* could not have been more wrong. Soon after the NACI report was issued, the Conservative government announced, as part of its April 2007 annual budget, that $300 million would be funneled

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[3] This is a thoughtful piece given the amount of sensationalized writing surrounding the vaccine that has circulated in the last six years since the approval of the vaccine in Canada; see for example, a 2007 *Maclean's* article entitled *Our Girls are not Guinea Pigs* by Gulli et al.

on a per capita basis to the provinces and territories "to help establish a national vaccine program that will help protect women and girls from cancer of the cervix" (April 16, 2007, Department of Finance press release). This press release positioned HPV and the HPV vaccine strictly as a women's-only issue.[4]

In early August 2007, the Ontario government followed suit and announced it would offer the HPV vaccine to grade eight girls free of charge in the public school system. In its official announcement, the provincial government proclaimed, "we're providing this vaccine to women at a young age so we can help prevent the spread of HPV and save lives" (August 2, 2007 press release, Office of the Premier:1). There is no mention in this release of HPV in connection with other genders or cancers, nor the part they play in the transmission of the virus. The Province of Ontario followed the federal lead in promoting the vaccine for use on women/girls only and as a means to "save" them from cancer. Premier Dalton McGuinty made the announcement in the lobby of Women's College Hospital in Toronto, flanked by female physicians in lab coats. Little did I know at the time that I would conduct a portion of my hospital-based fieldwork at this

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[4] This press release did not mention the connection between Merck Frosst and the governing Conservatives. A former staff member of the Prime Minister's inner circle, Ken Boessenkool, worked for the lobbying firm Hill+Knowlton and had acquired Merck Frosst as a client. Ken Boessenkool's linkage to both Merck Frosst and the government of the day were heatedly discussed in House of Commons debates (Priddy, House of Commons Debates, 2007, April 17) and numerous mainstream media outlets (Gillespie 2007, McGregor 2007, O'Malley 2007).

very hospital in 2010.[5] The Government of Ontario's public health program to provide vaccinations to grade eight girls in school settings is ongoing, although participation is tepid. For example, 40 percent of grade eight girls in Toronto did not receive the vaccination when it was offered to them in grade eight and so in early September 2012 Toronto Public Health announced that it would be delivering free vaccinations to teenage girls aged 14 to 19. The Province of Ontario agreed to provide funding for the Toronto Public Health Program (Bradley 2012). Interestingly, in April 2013, Prince Edward Island announced that it would fold boys into its existing grade-six vaccination program, which had previously been geared towards girls only. Prince Edward Island positioned this policy development as a benevolent act towards women. The Deputy Chief Public Health Officer, Dr. Lamont Sweet, was quoted as saying, "boys can be the source of the virus for their female partners. By preventing boys from carrying the virus, you in turn will prevent girls from getting the virus which causes cervical cancer" (CBC News, April 19 2013:1). A few weeks later, the Province of Alberta announced that it too was looking into offering the vaccine to boys alongside grade-five girls who were already offered the shot. According to *The Canadian Press*, Alberta Health was to investigate the proposal in depth during the summer of 2013 (Cotter 2013).

It is crucial to mention that during the period of federal and Ontario provincial endorsements of the vaccine for use in girls and women, scientific literature on HPV,

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[5] Fieldwork was conducted in collaboration with Sunnybrook Health Sciences Centre, but in the summer of 2010, the Sunnybrook Women and Babies program was housed at Women's College Hospital during the building of a new wing on their home campus.

particularly epidemiological studies, was gender blind. This literature, generally, focused on the linkage between HPV and male, female and multi-gendered cancers (see Munoz et al. 2006; Parkin and Bray 2006). Dr. Harold Zur Hausen, the Nobel Prize winner who discovered the link between HPV and cervical cancer, publicly questioned in 2008 (and he continues to question) the gendering of HPV-related vaccines and suggested boys should also be inoculated, as is public health policy in Austria (Zechmeister et al. 2010). In Canada in 2006, Dr. Gail Beck, then president of the Federation of Medical Women of Canada advocated for public, subsidized HPV vaccination campaigns to be available to both girls and boys. During a presentation to the federal Standing Committee on Finance in Ottawa on the HPV vaccine, she argued, "I would caution us to address this infection as one that is important to both men and women, thus the need to include both in any strategy. Clearly we need a national strategy that is informed by our diversity" (Standing Committee on Finance Proceedings, September 19, 2006:11).[6] In 2012 the Federation of Medical Women of Canada again made a call to "de-gender" (Paoletti 1997:27-35) the HPV vaccine; the current Federation president, Dr. Vivian Brown, was quoted by *The Canadian Press* as stating that, "both sexes contribute to the transmission of HPV. Both sexes are at risk of developing a variety of HPV-related diseases – including cancer. So it follows that both sexes should be protected. But currently, that's not the case" (Branswell 2012:1). The point here is that science/medicine did not gender HPV and the vaccine. This was a

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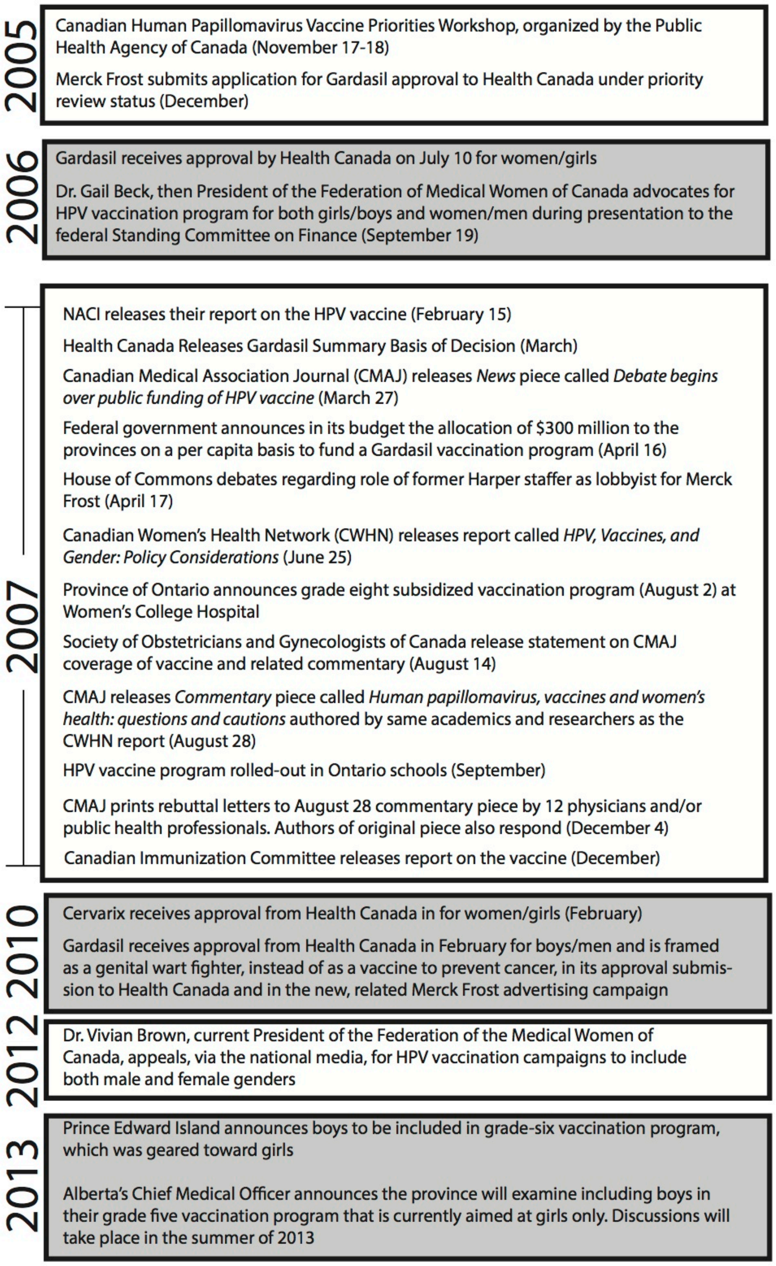
[6] It is disconcerting that public health issues are debated within the context of a federal Standing Committee on Finance and not within a health forum. This points to the increased corporatization of health policy.

governmental rendering; federal and provincial governments devised and carried out gendered policy, which was based on Merck Frosst's marketing lead.



Canadian Human Papillomavirus Vaccine Priorities Workshop, organized by the Public Health Agency of Canada (November 17-18)

Merck Frost submits application for Gardasil approval to Health Canada under priority review status (December)

Gardasil receives approval by Health Canada on July 10 for women/girls

Dr. Gail Beck, then President of the Federation of Medical Women of Canada advocates for HPV vaccination program for both girls/boys and women/men during presentation to the federal Standing Committee on Finance (September 19)

NACI releases their report on the HPV vaccine (February 15)

Health Canada Releases Gardasil Summary Basis of Decision (March)

Canadian Medical Association Journal (CMAJ) releases *News* piece called *Debate begins over public funding of HPV vaccine* (March 27)

Federal government announces in its budget the allocation of $300 million to the provinces on a per capita basis to fund a Gardasil vaccination program (April 16)

House of Commons debates regarding role of former Harper staffer as lobbyist for Merck Frost (April 17)

Canadian Women's Health Network (CWHN) releases report called *HPV, Vaccines, and Gender: Policy Considerations* (June 25)

Province of Ontario announces grade eight subsidized vaccination program (August 2) at Women's College Hospital

Society of Obstetricians and Gynecologists of Canada release statement on CMAJ coverage of vaccine and related commentary (August 14)

CMAJ releases *Commentary* piece called *Human papillomavirus, vaccines and women's health: questions and cautions* authored by same academics and researchers as the CWHN report (August 28)

HPV vaccine program rolled-out in Ontario schools (September)

CMAJ prints rebuttal letters to August 28 commentary piece by 12 physicians and/or public health professionals. Authors of original piece also respond (December 4)

Canadian Immunization Committee releases report on the vaccine (December)

Cervarix receives approval from Health Canada in for women/girls (February)

Gardasil receives approval from Health Canada in February for boys/men and is framed as a genital wart fighter, instead of as a vaccine to prevent cancer, in its approval submission to Health Canada and in the new, related Merck Frost advertising campaign

Dr. Vivian Brown, current President of the Federation of the Medical Women of Canada, appeals, via the national media, for HPV vaccination campaigns to include both male and female genders

Prince Edward Island announces boys to be included in grade-six vaccination program, which was geared toward girls

Alberta's Chief Medical Officer announces the province will examine including boys in their grade five vaccination program that is currently aimed at girls only. Discussions will take place in the summer of 2013

Figure 1: HPV Vaccine Policy Timeline in Canada

B] Harnessing Hegemonic Cultural Discourses of Risk and Gender

1. Merck Frosst's Gender-Based Marketing

Why is there an emphasis on vaccinating women in policy documents? In other words, why is HPV so clearly gendered in public health programming? The answers to these questions lie in the roll out strategy for the vaccine developed by Merck Frosst, that leads public health policy-making in an environment where there is little existing research on the prevalence, awareness, knowledge of or beliefs about HPV in Canada. In 2007, the magazine *Pharmaceutical Executive* awarded Merck Frosst its first "brand of the year" award for the Gardasil® campaign. The Gardasil® roll out strategy was three-pronged: first, to release the vaccine for nine- to 26-year-old girls and women; second, to focus on women aged 26 to 45; and, third, to make it available to boys and men (Herskovits 2007:70). Each phase of the strategy hinged upon gender-based analyses – gender cohorts were researched exhaustively and made the target of each section of the marketing campaign.[7] Merck Frosst's marketing campaign hinged on the gendering of HPV and positioning Gardasil® as a cancer fighting mechanism for women, side stepping the issue of sexual health and related cancers in other genders.

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[7] This is a common tactic in current marketing sciences and is called "segmented marketing" (Sheth et al. 2000).

Pharmaceutical Executive describes the marketing campaign as "play[ing] on cancer fears, but [drawing] on themes of safeguarding your children (for moms) and empowerment (for girls)" (Herskovits 2007:68). Merck Frosst conceived of and delivered a two-part advertising campaign. The first part, "Make the Connection," appeared prior to the approval of the vaccine and was intended to increase awareness of HPV. The second phase, post-approval, was a branding effort called "Tell Someone". It was intended to, "tap into 'women's natural inclination' as talkers and sharers" according to the Merck Frosst vice-president assigned the Gardasil® portfolio (Herskovits 2007: 68). The "Tell Someone" campaign evolved into the two types of Gardasil® advertisements that are circulating in Canada today: those targeting young women of university age (through television, magazines, large banners at university student centers, university sponsored day planners and posters in university washroom stalls); and those targeting the mothers of girls near the grade eight vaccination age and the girls themselves (through television and women's magazines). The "mom" campaign works to specifically support Ontario's official in-school HPV vaccination program.[8] (See figures 2 and 3 for marketing examples of both campaigns.)

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[8] As the Ontario government rolled out the school-based vaccination campaign, it did not initiate a public information campaign concerning HPV or the vaccine. Merck Frosst marketing campaigns filled that gap.

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Make the Connection is a public education campaign sponsored by the
Cancer Research and Prevention Foundation (CRPF) and Step Up Women's Network,
with support from Merck & Co., Inc.

To learn more, visit www.maketheconnection.org or call **1-888-4-HPV-CONNECT**.

maketheconnection

www.maketheconnection.org
1-888-4-HPV-CONNECT

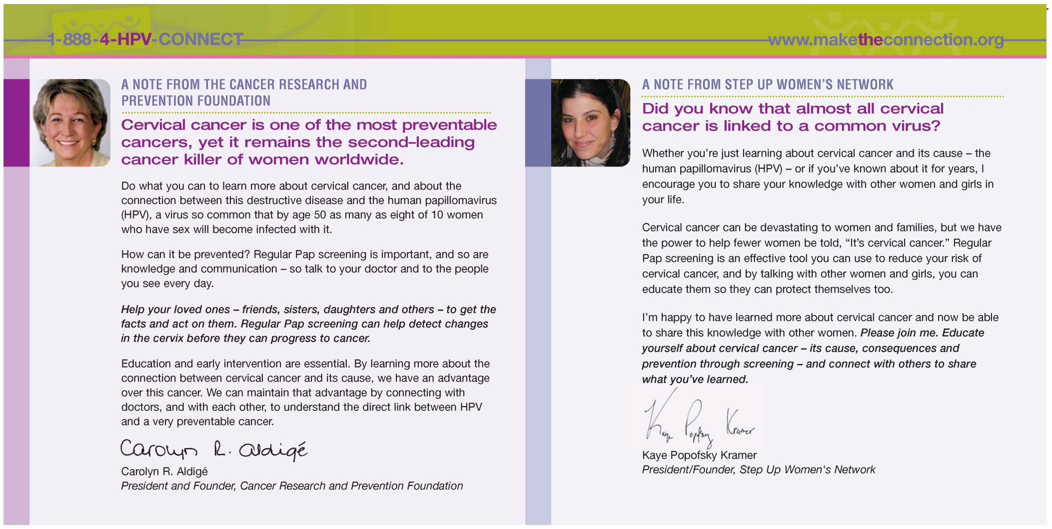
…between cervical cancer
and human papillomavirus (HPV)

How a common virus sometimes leads to cancer – and how you can help stop it

Cancer Research and Prevention Foundation
www.preventcancer.org

stepup
women's network

With support from Merck & Co., Inc.



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A NOTE FROM THE CANCER RESEARCH AND PREVENTION FOUNDATION

Cervical cancer is one of the most preventable cancers, yet it remains the second-leading cancer killer of women worldwide.

Do what you can to learn more about cervical cancer, and about the connection between this destructive disease and the human papillomavirus (HPV), a virus so common that by age 50 as many as eight of 10 women who have sex will become infected with it.

How can it be prevented? Regular Pap screening is important, and so are knowledge and communication – so talk to your doctor and to the people you see every day.

Help your loved ones – friends, sisters, daughters and others – to get the facts and act on them. Regular Pap screening can help detect changes in the cervix before they can progress to cancer.

Education and early intervention are essential. By learning more about the connection between cervical cancer and its cause, we have an advantage over this cancer. We can maintain that advantage by connecting with doctors, and with each other, to understand the direct link between HPV and a very preventable cancer.

Carolyn R. Aldigé

Carolyn R. Aldigé
President and Founder, Cancer Research and Prevention Foundation

A NOTE FROM STEP UP WOMEN'S NETWORK

Did you know that almost all cervical cancer is linked to a common virus?

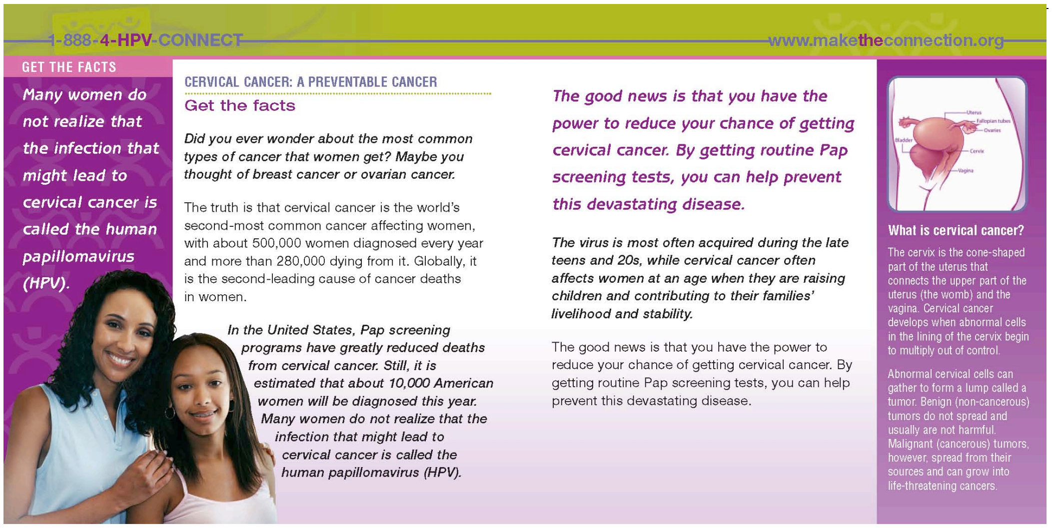
Whether you're just learning about cervical cancer and its cause – the human papillomavirus (HPV) – or if you've known about it for years, I encourage you to share your knowledge with other women and girls in your life.

Cervical cancer can be devastating to women and families, but we have the power to help fewer women be told, "It's cervical cancer." Regular Pap screening is an effective tool you can use to reduce your risk of cervical cancer, and by talking with other women and girls, you can educate them so they can protect themselves too.

I'm happy to have learned more about cervical cancer and now be able to share this knowledge with other women. *Please join me. Educate yourself about cervical cancer – its cause, consequences and prevention through screening – and connect with others to share what you've learned.*

Kaye Popofsky Kramer

Kaye Popofsky Kramer
President/Founder, Step Up Women's Network



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GET THE FACTS

Many women do not realize that the infection that might lead to cervical cancer is called the human papillomavirus (HPV).

CERVICAL CANCER: A PREVENTABLE CANCER

Get the facts

Did you ever wonder about the most common types of cancer that women get? Maybe you thought of breast cancer or ovarian cancer.

The truth is that cervical cancer is the world's second-most common cancer affecting women, with about 500,000 women diagnosed every year and more than 280,000 dying from it. Globally, it is the second-leading cause of cancer deaths in women.

In the United States, Pap screening programs have greatly reduced deaths from cervical cancer. Still, it is estimated that about 10,000 American women will be diagnosed this year. Many women do not realize that the infection that might lead to cervical cancer is called the human papillomavirus (HPV).

The good news is that you have the power to reduce your chance of getting cervical cancer. By getting routine Pap screening tests, you can help prevent this devastating disease.

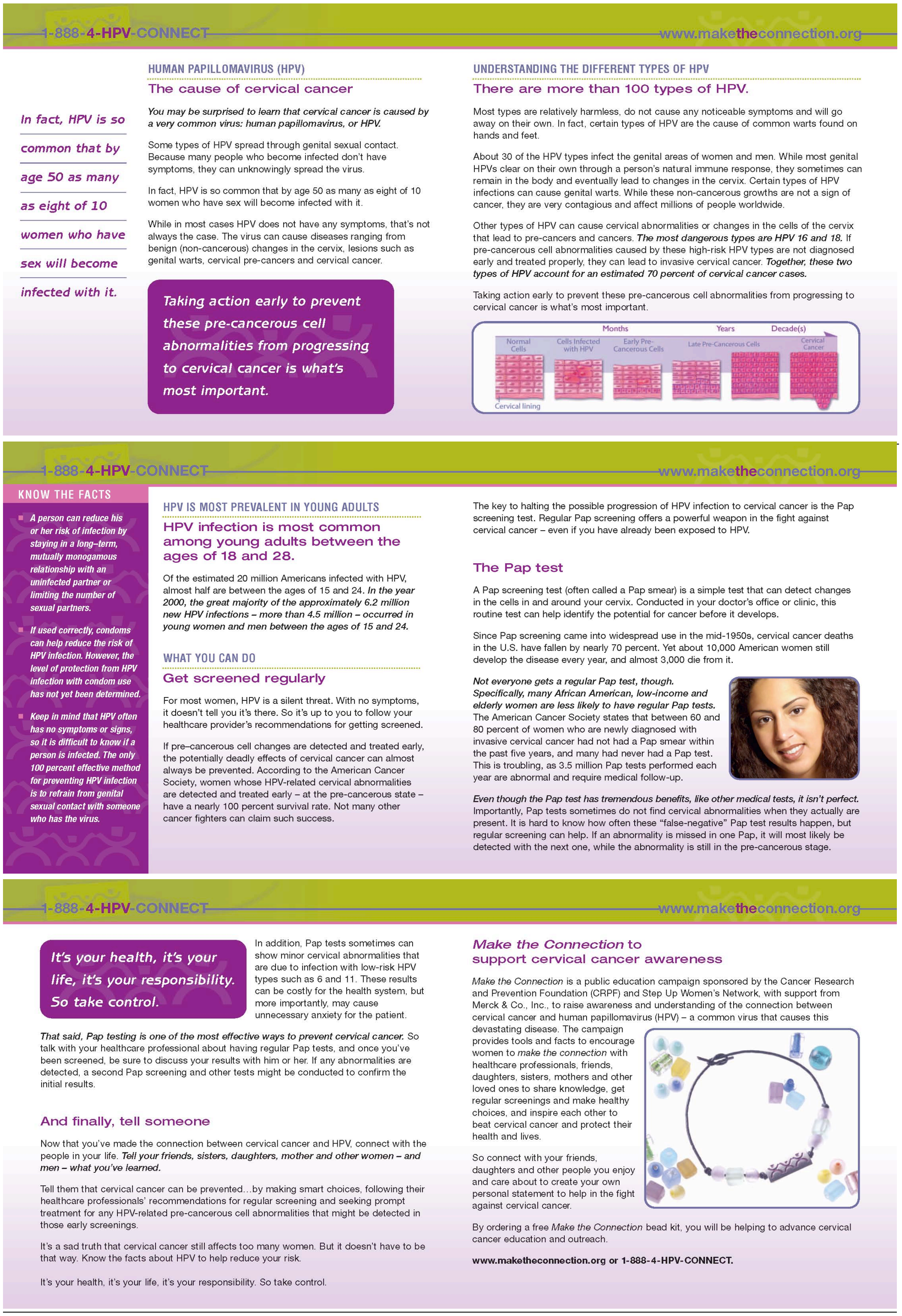
The virus is most often acquired during the late teens and 20s, while cervical cancer often affects women at an age when they are raising children and contributing to their families' livelihood and stability.

The good news is that you have the power to reduce your chance of getting cervical cancer. By getting routine Pap screening tests, you can help prevent this devastating disease.

What is cervical cancer?

The cervix is the cone-shaped part of the uterus that connects the upper part of the uterus (the womb) and the vagina. Cervical cancer develops when abnormal cells in the lining of the cervix begin to multiply out of control.

Abnormal cervical cells can gather to form a lump called a tumor. Benign (non-cancerous) tumors do not spread and usually are not harmful. Malignant (cancerous) tumors, however, spread from their sources and can grow into life-threatening cancers.



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In fact, HPV is so common that by age 50 as many as eight of 10 women who have sex will become infected with it.

HUMAN PAPILLOMAVIRUS (HPV)

The cause of cervical cancer

You may be surprised to learn that cervical cancer is caused by a very common virus: human papillomavirus, or HPV.

Some types of HPV spread through genital sexual contact. Because many people who become infected don't have symptoms, they can unknowingly spread the virus.

In fact, HPV is so common that by age 50 as many as eight of 10 women who have sex will become infected with it.

While in most cases HPV does not have any symptoms, that's not always the case. The virus can cause diseases ranging from benign (non-cancerous) changes in the cervix, lesions such as genital warts, cervical pre-cancers and cervical cancer.

Taking action early to prevent these pre-cancerous cell abnormalities from progressing to cervical cancer is what's most important.

UNDERSTANDING THE DIFFERENT TYPES OF HPV

There are more than 100 types of HPV.

Most types are relatively harmless, do not cause any noticeable symptoms and will go away on their own. In fact, certain types of HPV are the cause of common warts found on hands and feet.

About 30 of the HPV types infect the genital areas of women and men. While most genital HPVs clear on their own through a person's natural immune response, they sometimes can remain in the body and eventually lead to changes in the cervix. Certain types of HPV infections can cause genital warts. While these non-cancerous growths are not a sign of cancer, they are very contagious and affect millions of people worldwide.

Other types of HPV can cause cervical abnormalities or changes in the cells of the cervix that lead to pre-cancers and cancers. ***The most dangerous types are HPV 16 and 18.*** If pre-cancerous cell abnormalities caused by these high-risk HPV types are not diagnosed early and treated properly, they can lead to invasive cervical cancer. ***Together, these two types of HPV account for an estimated 70 percent of cervical cancer cases.***

Taking action early to prevent these pre-cancerous cell abnormalities from progressing to cervical cancer is what's most important.

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KNOW THE FACTS

- ***A person can reduce his or her risk of infection by staying in a long–term, mutually monogamous relationship with an uninfected partner or limiting the number of sexual partners.***
- ***If used correctly, condoms can help reduce the risk of HPV infection. However, the level of protection from HPV infection with condom use has not yet been determined.***
- ***Keep in mind that HPV often has no symptoms or signs, so it is difficult to know if a person is infected. The only 100 percent effective method for preventing HPV infection is to refrain from genital sexual contact with someone who has the virus.***

HPV IS MOST PREVALENT IN YOUNG ADULTS

HPV infection is most common among young adults between the ages of 18 and 28.

Of the estimated 20 million Americans infected with HPV, almost half are between the ages of 15 and 24. ***In the year 2000, the great majority of the approximately 6.2 million new HPV infections – more than 4.5 million – occurred in young women and men between the ages of 15 and 24.***

WHAT YOU CAN DO

Get screened regularly

For most women, HPV is a silent threat. With no symptoms, it doesn't tell you it's there. So it's up to you to follow your healthcare provider's recommendations for getting screened.

If pre–cancerous cell changes are detected and treated early, the potentially deadly effects of cervical cancer can almost always be prevented. According to the American Cancer Society, women whose HPV-related cervical abnormalities are detected and treated early – at the pre-cancerous state – have a nearly 100 percent survival rate. Not many other cancer fighters can claim such success.

The key to halting the possible progression of HPV infection to cervical cancer is the Pap screening test. Regular Pap screening offers a powerful weapon in the fight against cervical cancer – even if you have already been exposed to HPV.

The Pap test

A Pap screening test (often called a Pap smear) is a simple test that can detect changes in the cells in and around your cervix. Conducted in your doctor's office or clinic, this routine test can help identify the potential for cancer before it develops.

Since Pap screening came into widespread use in the mid-1950s, cervical cancer deaths in the U.S. have fallen by nearly 70 percent. Yet about 10,000 American women still develop the disease every year, and almost 3,000 die from it.

Not everyone gets a regular Pap test, though. Specifically, many African American, low-income and elderly women are less likely to have regular Pap tests. The American Cancer Society states that between 60 and 80 percent of women who are newly diagnosed with invasive cervical cancer had not had a Pap smear within the past five years, and many had never had a Pap test. This is troubling, as 3.5 million Pap tests performed each year are abnormal and require medical follow-up.

Even though the Pap test has tremendous benefits, like other medical tests, it isn't perfect. Importantly, Pap tests sometimes do not find cervical abnormalities when they actually are present. It is hard to know how often these "false-negative" Pap test results happen, but regular screening can help. If an abnormality is missed in one Pap, it will most likely be detected with the next one, while the abnormality is still in the pre-cancerous stage.

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It's your health, it's your life, it's your responsibility. So take control.

In addition, Pap tests sometimes can show minor cervical abnormalities that are due to infection with low-risk HPV types such as 6 and 11. These results can be costly for the health system, but more importantly, may cause unnecessary anxiety for the patient.

That said, Pap testing is one of the most effective ways to prevent cervical cancer. So talk with your healthcare professional about having regular Pap tests, and once you've been screened, be sure to discuss your results with him or her. If any abnormalities are detected, a second Pap screening and other tests might be conducted to confirm the initial results.

And finally, tell someone

Now that you've made the connection between cervical cancer and HPV, connect with the people in your life. ***Tell your friends, sisters, daughters, mother and other women – and men – what you've learned.***

Tell them that cervical cancer can be prevented…by making smart choices, following their healthcare professionals' recommendations for regular screening and seeking prompt treatment for any HPV-related pre-cancerous cell abnormalities that might be detected in those early screenings.

It's a sad truth that cervical cancer still affects too many women. But it doesn't have to be that way. Know the facts about HPV to help reduce your risk.

It's your health, it's your life, it's your responsibility. So take control.

Make the Connection to support cervical cancer awareness

Make the Connection is a public education campaign sponsored by the Cancer Research and Prevention Foundation (CRPF) and Step Up Women's Network, with support from Merck & Co., Inc., to raise awareness and understanding of the connection between cervical cancer and human papillomavirus (HPV) – a common virus that causes this devastating disease. The campaign provides tools and facts to encourage women to *make the connection* with healthcare professionals, friends, daughters, sisters, mothers and other loved ones to share knowledge, get regular screenings and make healthy choices, and inspire each other to beat cervical cancer and protect their health and lives.

So connect with your friends, daughters and other people you enjoy and care about to create your own personal statement to help in the fight against cervical cancer.

By ordering a free *Make the Connection* bead kit, you will be helping to advance cervical cancer education and outreach.

www.maketheconnection.org or 1-888-4-HPV-CONNECT.

Figure 2 - "Make the Connection" Pamphlet/Advertorial

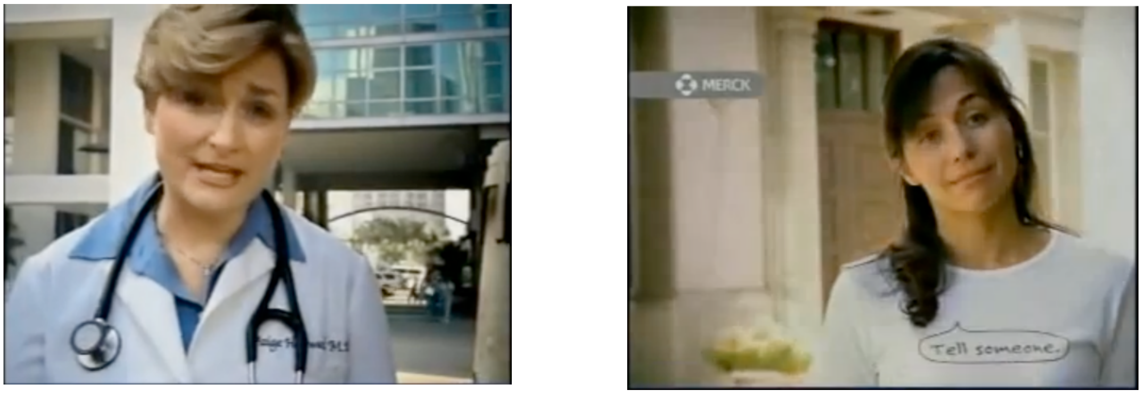

Figure 3 – "Tell Someone" Campaign Commercial

The television advertisement featured in figure 3 is transcribed below.

Woman 1 (Latino-looking woman in late 30s or early 40s): *Well, it's a cancer caused by a virus. I mean, I can't get over that. I want to tell anyone.*

Woman 2 (Latino-looking woman, university age): *I just found out cervical cancer is caused by certain types of a common virus. Cancer caused by a virus: HPV. The Human Papillomavirus. I didn't know that.*

Woman 3 (Light-skinned woman of Afro-Caribbean descent, mid-30s): *I was stunned at how many people have HPV. I'm stunned. Millions, millions – that's insane.*

Woman 4 (White physician, mid-40s, wearing white lab coat with stethoscope around neck): *For most women HPV clears on its own, but for some cervical cancer can develop.*

Woman 5 (Light-skinned woman of Afro-Caribbean descent with a "tween"-aged daughter): Voice over says the following – *That's why it's important to talk to your doctor about Pap tests.*

Woman and daughter do not speak during this shot. At bottom of screen the following text appears: *Tell-someone.com 877-NOW-TELL.*

Woman 6 (White, mid-30s): *I feel like it's my responsibility just to tell everyone I know.*

Woman 7 (Latino-looking, mid-30s): *I just want to tell someone I love. I want to tell my sister. I want to tell my mom. I want to tell everyone I know.*

Woman 8 (same woman as #7, but wearing different clothes): *Tell Someone.*

Woman is wearing a t-shirt with *Tell Someone* on the front. The advertisement ends with this image.

2. Sales/Governance Strategies

How can a pharmaceutical branding campaign gender a virus and subsequent public health programming? It is not simply that the multi-national pharmaceutical corporation with the most dollars or persuasive lobbyists triumphs. Rather, the situation is more complex – economic power is embedded in, and not above, social, cultural and historical processes (Morrison 1995:320). In this specific case, Merck Frosst strategically harnessed western hegemonic cultural logics and discourses surrounding risk and gender in order to develop marketing campaigns to sell its vaccine. This was a two-part process which involved: (1) circulating HPV-related information that leveraged cultural logics surrounding risk and gender in order to brand HPV as a woman-only concern and (2) arranging consumer buy-in through self-regulation. The first step was to disseminate HPV-related "expert knowledge" (Foucault 1989:52). As publicly available government information on the vaccine was limited, Merck Frosst readily filled that void. Merck Frosst used the advertorial, "Make the Connection", (figure 2) to inform women about HPV. It contains information on cervical cancer, what HPV is and the many different HPV strains. This information is supported by statistics of the global incidence of cervical cancer, an anatomical drawing of a woman's reproductive system and endorsements provided by leaders in the field of women's health in the United States. While this is a paid advertisement, it reads and looks as though it is a medical information brochure.

Figure 3 provides a transcript and two still shots of a television advertisement for the "Tell Someone" component of the Gardasil® marketing campaign. This advertisement, like the "Make the Connection" advertorial, also aims to inform women about HPV, particularly the trajectory of the virus, whether it "clears on its own" or turns into cervical cancer. Both examples of Gardasil® marketing urge women to take an active role in preventing HPV. The "Make the Connection" advertorial states: "It's your health, it's your life. So take control." Taking control in the advertorial involves visiting a physician to regularly undergo a Pap test. Taking control in the "Tell Someone" commercial involves spreading the word about HPV – telling the women you know about it and speaking to a physician about Pap testing. It is important to note that these two advertisements were developed and released prior to the approval of Gardasil® by the Food and Drug Administration (FDA) in the United States. Because of this Merck Frosst was not able to mention the Gardasil® vaccine by name in its advertisements. The next wave of Gardasil® advertising, post-FDA approval, is discussed in chapters four and five. Chapter Four features a Gardasil® "mom" advertisement (figure 5), which depicts a mother and a daughter, and urges the mother to talk to her doctor about her daughter's vaccination. Chapter Five includes a post-approval Gardasil® advertisement aimed at female university students (figure 7). This advertisement encourages female students to visit their campus health clinics to get vaccinated. The knowledge of HPV provided in the pre-approval advertisements and the push to get women vaccinated in the post-approval advertisements work together to scare women about HPV and to create a "need" for inoculation against HPV.

The second step involved getting consumer buy-in, literally. Merck Frosst created such a need for the vaccine in its multiple advertising campaigns that consumers asked their doctors for it. This is a common tactic of pharmaceutical companies and is called direct-to-consumer advertising (Mintzes 2010). This tactic is essentially pharmaceutically directed self-regulation. As such, Gardasil® sales tactics also function as governance strategies. Such a governance approach works to deploy "a mode of power par excellence designed to produce a market-based notion of agency and subjectivity" (Giroux 2010:30). To critique this governance strategy, I am employing Foucault's concept of governmentality (1991). The governmentality approach to risk focuses on how governments "work together to govern – that is, manage and regulate – populations via risk discourses and strategies" (Lupton, 1999a: 1).[9] Governmentality is not necessarily about governmental institutions, though. Instead it is about their ability through "persuasion" to get those they are governing to enact their policies and directives (Giroux 2010:51-52). Within the current, contemporary climate of "new"[10]

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[9] At the beginning of Chapter Three the rationale for utilizing a governmentality approach to risk in the analysis of the archival portion of the research project will be explained.

[10] Nettleton (1996) calls this the "rise of a psycho-socio-environmental/epidemiological model" (34), which has replaced the biomedical approach. This shift results in moving away from treating disease to preventing disease. Prevention policy, which is delivered

public health that emphasizes neo-liberal devolution of governmental responsibility (Lupton and Petersen 1996), governing approaches focus more and more on "the art of self-government, connected with morality" (Foucault, 1991:91). As such, preventative strategies, or "technologies of power" (Foucault, 1999:14), center on the promotion of self-regulation, which works to attain and maintain an idealized form of self (Turner 1997). Contemporary health discourse focuses on a version of the self "that is autonomous, subjective and active" (Nettleton 1997:209). In other words, it is up to *you* to ensure that *you* meet the standards of health and to manage any potential health risks. Thus, if a person falls sick, it is due to their lack of self-restraint. Idealized conceptualizations of the self are then steeped in the notions of self-discipline and the ability to continually reinforce an identity that promotes one's health.

All individuals are expected to be "active citizens," whether or not they are actually part of "targeted populations" (Dean 1997:147), albeit, the lines between those who are targeted and those who are not are porous – all can be at-risk at anytime. This is part and parcel of the "colonization of the future" (Giddens 1991:117, 182) whereby risk has become a foundational tenet of governance strategies. As such, "it seems that we are no longer simply concerned with the governance *of* risk but we are now in an era of governance *by* risk" (Rothstein 2006:216, emphasis in the original). Governance

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via health promotion strategies, is predicated upon the tenets of "'risk', 'surveillance', and the 'rational self'" (Nettleton 1996:34).

through pre-detection, or creating what Rose[11] calls “pre-patients” (2007:20) opens up increasingly fertile ground for surveillance (Castel 1991:288).

The expansive surveillance mandate of the new public health functions by “mainly incorporate[ing] voluntary actions on the part of citizens but also [by] us[ing] legislation, much of which is enshrined in public health acts” (Lupton and Petersen 1996:5). As is seen with the Gardasil® campaigns, women are urged to accept greater responsibility for their health through direct-to-consumer advertising. But Gardasil® sales are also ensured because of the Ontario province-wide grade eight public school vaccination program for girls. As the Province of Ontario did not initiate a public information campaign alongside the grade eight programming, Merck Frosst’s multi-pronged Gardasil® advertising campaigns worked to ensure that a need for the vaccine was maintained. In the case of Gardasil®, the responsibility for the health of the population was no longer *entirely* under the purview of the state. While the responsibility for keeping risk at bay is that of the individuals, what is deemed to be a risk is established through the joint workings of the pharmaceutical company and policy-making processes. Together they create a guaranteed market for the sale of the

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[11] In his work on risk and governmentality, Rose puts forth the notion of biological citizenship (Rose and Novas 2002). In biological citizenship, governmentality is linked to governance via the body (Rose and Novas 2002:2). Biological citizenship follows the dominant trend in risk theory literature as it does not critically address gender. As is discussed in Chapter Seven, “situated risk” (Boholm 2003:158) provides more fertile ground through which to pursue risk and gender in tandem. Moreover, Giroux posits that in the current neo-liberal landscape, individuals are organized not “as citizens but as consumers” (2010:2).

product. This would not happen, however, if prevailing cultural logics did not support the notion of women being perpetually at-risk.

3. Deploying Gender as Risk

In the case of the HPV vaccine being a certain gender puts one at risk. As a girl/woman being female positions you as needing particular protection from cancer stemming from HPV, yet this not deemed necessary for men. Douglas asserts that "arguments about risk are highly charged, morally and politically" (2002[1966]: xix). As such, the attribution of being at-risk for potential illness encourages moral governance through the framing and fixing of difference. This morality is used to keep those who threaten the social order – or the equilibrium of those in power – safely within their pre-determined "box" (Douglas 2002[1966]:125, 172).[12] When in a box, those at-risk can be contained and governed. When placed within the box, one has to follow the rules or norms. The norm "is not simply and not even a principle of intelligibility; it is an element on the basis of which a certain exercise of power is founded and legitimized . . . Perhaps we could say it is a political concept" (Foucault 1999:50).[13] Thus, this at-risk categorization reflects not only women's subordinate status in western society, but also works to maintain this subordination. The cultural messaging surrounding the HPV

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[12] Douglas refers to "Chinese-box-like" structures, where boxes fit within boxes, each indicating the multiple layers of derivative structures sitting within the overall structure, or the main box, a metaphor for society as a whole (2002[1966]:125).

[13] Foucault is drawing upon Canguilhem's (1989) work on the normal versus abnormal in this discussion.

vaccine, both in the pharmaceutical marketing campaigns and the Ontario government policy of subsidizing in-school vaccination for girls only, works to keep women and girls firmly in their at-risk box. This is a governance strategy to keep women in their place in the social hierarchy – it does not relegate them to the margins, but keeps them firmly tucked away from spheres of influence.

There is, of course, a long history of keeping women in their place through being labeled at-risk. In medicine, as in society, women have been portrayed as “especially threatening to the moral order and social stability of society, largely due to the seemingly uncontrollable and dangerous nature of their sexuality” (Lupton 2003:143). Douglas elaborates further:

> Such patterns of sexual danger can be seen to express symmetry or hierarchy. It is implausible to interpret them as expressing something about the actual relation of the sexes. I suggest that many ideals about sexual dangers are better interpreted as symbols of relation between parts of society, as mirroring designs of hierarchy or symmetry, which apply in the larger social system. [2002(1966):4]

In other words, positioning women as sexually threatening is not reflective of gender relations – those between men and women within a heterosexual framework – but of society’s tendency to classify and find a place for everyone so as to not disturb existing power structures. Correspondingly, for several hundred years, women have been positioned as the “other” in medicine, unwell and inferior to men (Lupton 2003:143). Women have been, and continue to be, portrayed as faint-hearted, prone to disease, the vessels for spreading sexually transmitted infections and the cause of emotional turmoil for their children. Medicine has woven the tale that women are tautologically passive receptors of disease and active, deleterious agents of disease (Lupton 2003:143). Women are represented as such in medical textbooks. For example, Martin (2007) reports that medical texts depict male and female reproductive organs as “systems of production,” but frame male organic matter in an active and positive light, all the while depicting female organic matter in disparaging terms (417). Sperm is generally described as being “produced,” whereas, “ova merely sit on the shelf, slowly degenerating and aging like overstocked inventory” (Martin 2007:418). Sperm is also depicted as “penetrating the egg” through “mechanical and chemical means” after the egg has “drifted along the fallopian tube” (Martin 2007:420-421). Martin finds that such imagery haunts historical and contemporary re-presentations, even when research has detected new patterns of reproduction. For example, in spite of the discovery by John Hopkins scientists that the sperm and egg adhere similarly to positive and negative strips of Velcro, the process is still described using the old imagery. Martin explains:

> Although this new version of the saga of the egg and the sperm broke through cultural expectations, the researchers who made the discovery continued to write papers and abstracts as if the sperm were the active party who attacks, binds, penetrates, and enters the egg. The only difference was that the sperm were now seen as performing these actions weakly. [2007:421]

Likewise, Lawrence and Bendixen (1992) note that medical textbooks, from the late 1890s to the late 1980s, depict male and female forms in a similar manner. Anatomical imagery and accompanying text place a primacy on male bodies by using these bodies as the ideal benchmark and then describe female bodies through the ways they differ from the male "standard." These cultural conceptualizations also translate into medical practice. Gynecology, as a medical specialty, holds no equivalent area of research or service for men even though they possess their own specific set of genitalia. As such, female genitalia are classified as risky and are subjected to surveillance throughout a women's lifecycle. Hanson notes that other potential cancer sites, such as the "liver, pancreas, lymph glands, lung, kidney, or other less accessible organs" are not accorded the same surveillance (2000:60). Correspondingly, women are routinely screened for breast and cervical cancer due to their unique at-risk status and because these areas are simple to reach (Kaufert 2000). Hanson notes, "this opens up the possibility that genitalia focus in cancer may be as much a case of what is routinely screened rather than what is ultimately most dangerous" (2000:60). That being said, gynecology continues be a way in which medicine constructs risk in women which cannot be construed in men. Gynecology keeps women "visible"(Foucault 1989:111) in medicine and continual "subjects" of surveillance and control (Lupton 2003:161).

Thus, the sexually active, "feminine" body (Bartky 1990) was (and is) viewed as needing to be monitored and sheltered from harm. Protecting oneself is not thought to come "naturally" for the "weaker", second sex.[14] But making genitalia and sexual activity visible is also a long-standing governance technique. Foucault notes that instead of "repressing" the subject of sex, modern power structures amplify it

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[14] This is a not very subtle reference to de Beauvoir's well-known tome (1989[1952]).

(1990[1978]:72). He urges readers to look at how power functions in "positive mechanisms, insofar as they produce knowledge, multiply discourse, induce pleasure, and generate power" (1990[1978]:73). It is through promoting discussion about sex, sexuality and gender that power structures are able to make women visible and simultaneously keep them within the box Douglas speaks of (2002[1966]). But with the case of the HPV vaccine, early research based in the United States indicates that parents are not likely to vaccinate their daughters if they feel that the vaccine promotes adolescent sexuality (Constantine et al. 2007; Dekker 2006; Olshen et al. 2005). In some studies parents even described the vaccine as a means of promoting and encouraging adolescent sexuality, a concept they were clearly uncomfortable with. Given this research, Merck Frosst did not harness tried and true methods of highlighting women's sexual risk or risks relating to sexuality, that is, focusing upon HPV as an STI. Instead, Merck Frosst chose to frame HPV solely as a cancer-causing virus – one that specifically causes cervical cancer – and sidestepped the fact that HPV is transmitted through sexual contact, including genital touching (Burchell et al. 2011,Vanslyke et al. 2008). Merck Frosst was well aware that positioning the HPV vaccine as a tool to fight STI in girls/women was not a smart marketing move; in this case, sex would not sell.[15] Instead, Merck Frosst developed a strategy to sell the vaccine by playing upon cultural notions of the "female" who needs to be protected from cancer. Mixing the cultural notions of the "weaker" sex that must be protected and cancer as a frightening,

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[15] Sex, of course, was meant to sell when Merck Frosst introduced an advertising campaign for the use of the vaccine in young men in 2012. This campaign positioned Gardasil® as a genital wart fighter for its male customers (Merck Frosst 2011a).

mysterious and omnipresent illness[16] (Sontag 1999) was the perfect marketing prescription. In Merck Frosst's marketing of the HPV vaccine, cancer kept girls/women visible but sex invisible. Even though this tactic differs slightly from Foucault's summation of visibility and sexual relations, the power technique employed reflects Foucault's ideas. It is also interesting to note that Merck Frosst focused on cervical cancer and not vaginal, vulvar, anal or throat cancer in women. This is because cervical cancer is an easier cultural sell than the other cancers associated with HPV.

As will be discussed below, the main tenets of Merck Frosst's marketing campaign – the gendering of the vaccine and its positioning as a cancer panacea – spilled over into Canadian public health policy making. Some may call this the "pharmaceuticalization of public health" (Biehl 2007:222), but it can be argued that this is really a case of the replication of hegemonic conceptualizations of gender and risk in policy making. Merck Frosst was the first to deploy these governance techniques as a selling mechanism, but if these conceptualizations were not in the ether, they would not have been picked up again in policy making. The policy sphere, as with all other facets of daily life, is rife with the circulating, yet static, cultural "ideals" of gender and risk.

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[16] I am not stating that cancer is not a terrible illness for those who suffer from it. Rather, I am pointing to a very specific set of western cultural notions and logics about cancer that are emotionally charged and that Merck Frosst leveraged in the selling of its vaccine: cancer is feared, not widely understood, most individuals know or know of someone who has suffered from cancer and this is a disease all parents wish to protect their children from.

4. Gender-Based Analyses (GBA) in Policy Making

Policy documents indicate that government officials at the federal level[17] examined the issue of the HPV vaccine within a GBA frame (Greaves 2009; Health Canada 2000, 2003a, 2003b; House of Commons 2005; Status of Women Canada 2004; Tudiver 2009). GBA is a policy development approach that the federal government has been using since the mid-1990s. The federal government first committed itself to using GBA in 1995 in conjunction with the 4th World Conference on Women held in Beijing. That same year the federal government released *The Federal Plan for Gender Equality* (1995), a cornerstone document mapping the federal government's blueprint for GBA implementation.[18] In 1999, Health Canada specifically committed itself to using GBA while developing policy and programs. In 2003 Health Canada implemented a five-year plan to ensure that GBA would be in "full-effect" across departmental initiatives (Health Canada 2003a:2). The goal of implementing GBA is to bring about gender equality in government programming and, hence, to the country as a whole (Hankivsky 2012). As the name indicates, GBA places a primacy on "gender as an essential variable in policy analysis" (Hankivsky 2012:172). Thus, gender is the pivotal axis

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[17] While theoretically health is under provincial jurisdiction in Canada, the drive to bring the HPV vaccine to Canada occurred at the federal level. Not only is the federal government charged with approving pharmaceutical products, it is also responsible for allocating the initial $300 million for transfer to the provinces on a per capita basis to get the vaccination programs started.

[18] The critique of GBA featured here is meant to apply only to the case study of the HPV vaccine in Canada. GBA is a framework used in many disciplines, such as development studies, and research regarding the vaccine is not intended to speak for the conceptualization or implementation of GBA in other circumstances.

through which policy is analyzed and programs are developed, regardless of their aims or orientation. Health Canada defines GBA as:

> An analytical tool that systematically integrates a gender perspective into the development of policies, programs and legislation, as well as planning and decision-making processes. It helps to identify and clarify the difference between women and men, boys and girls, and demonstrates how these differences affect health status, access to, and interaction with, the health care system. [Health Canada 2003a:1]

Health Canada also describes GBA as, “a catalyst for change” by ensuring that a “gender equality perspective” is folded into the development of health policy (2003b:1). Health Canada also uses GBA “to promote sound scientific research, and provide relevant health information and evidence” (2003b:1). Accordingly, the framework has been adopted in women’s health research conducted at Canadian universities and non-profit, health-oriented organizations (Abramson 2009; Jackson et al. 2009; O’Sullivan and Amaratunga 2009). Such studies have examined topics as far reaching as wait times for surgery, diagnostic tests and communicable disease outbreaks.

Within health research and program design, GBA is a tool that amplifies the difference between men and women and puts in place “a semblance of order,” where, on the ground, difference is often difficult to demarcate (Douglas 2002 [1966]:5). Such a move works to “impose system on an inherently untidy experience” (Douglas 2002 [1966]:5). Therefore, conceptually, GBA in health research and program design pits men against women, views them as undifferentiated “wholes” and places a primacy on the effects of gender on health. Hankivsky (2012) argues that much debate has taken place over the adoption and application of GBA in health research and program design, but not much discussion has been focused on the underlying theoretical tenets of the framework. Hankivsky critiques GBA in health research and program design for its conceptual treatment of gender. In practice, the reference to gender within prevailing health-oriented GBA frameworks generally refers to women and not men. This pragmatic application of GBA is evident in the December 2007 Canadian Immunization Committee (CIC) report on the HPV vaccine. This CIC report focused on cost-effective analyses of the vaccine, a common policy exercise that is often an analytical subset of a GBA. The cost-effectiveness model aims to develop policy that reaches the widest audience possible with "tangible" health benefits, all the while containing costs (Hankivsky 2007a). Vaccination programs tend to fare well in this type of analysis because the outcomes are simple to measure – the number of individuals vaccinated can easily be tallied. The first cost-effective analysis in the CIC report focuses on females only, although the report does cite many studies in the bibliography on HPV that include both females and males (2007). The authors chose not to bring this data into their analysis, thereby invoking gendering from the very beginning of the policy-making process. The second cost-effectiveness analysis in the CIC report includes boys, but no mention is made of potential HPV-related cancer rates in boys. In this analysis the HPV vaccine is presented as an "altruistic" (Epstein 2010:75) vaccine and HPV as a "woman's issue"– boys should be vaccinated to help eradicate cervical cancer in women. A third cost-effectiveness analysis document has also been circulating, but was prepared by a consulting firm for the Public Health Agency of Canada (Krueger 2008). This report was not presented as a Public Health Agency of Canada document, but nevertheless was funded by the Agency. This report also examines the cost-effectiveness of vaccinating girls and the eventual influences upon cervical cancer mortality rates. It concludes that there is no evidence to suggest that vaccinating boys will significantly reduce cervical cancer mortality (Krueger 2008:32). Therefore, in these GBA modeling exercises, the ideal of "gender equality" translates into positioning women as needing much more assistance than their male counterparts, with women occupying a homogenous and static contingent of society, whose very essence – gender – puts them at risk. In this sense, HPV vaccine-related policy processes have reinforced circulating gender norms, as many health policies do (Moore 2010).

In addition to a lack of focus on both women and men, cost-effectiveness analyses do not invoke any form of "diversity analysis" (Hankivsky 2007b:156) as it plays out within a gender grouping. For example, how does a woman's age, marital status, religion, geographic location or income level affect her ability to take advantage of a specific program? As a case in point, women who do not have access to regular Pap screenings, such as Aboriginal, racialized, immigrant, homeless and other marginalized girls and women, are more susceptible to developing cervical cancer and make up a large portion of the approximately 400 cervical cancer deaths in Canada each year (CWHN 2007). The issues these marginalized women face are not addressed in current HPV-related policy in Canada or Ontario. Thus, the concept of "female" that is plugged into HPV vaccine-oriented GBA frameworks insinuates that all women will encounter health related challenges and barriers, regardless of class, race, age, educational, religious or geographical standing. GBA relies upon the "assumption – either made implicitly or explicitly – that gender is the most frequent[ly] occurring, structural and important inequality for consideration" (Hankivsky 2012:174).

It is only fair to mention, though, that early GBA documentation does make reference to "diversity" among women. For example, *The Federal Plan for Gender Equality* (1995) states that:

> A gender-based approach ensures that the development, analysis and implementation of legislation and policies are undertaken with an appreciation of gender differences. This includes an understanding of the nature of relationships between men and women, and the different social realities, life expectations and economic circumstances facing women and men. It also acknowledges that some women may be disadvantaged even further because of their race, colour, sexual orientation, socio-economic position, region, ability level or age. A gender-based analysis respects and appreciates diversity. [19]

This perspective, unfortunately, has not been applied in the HPV vaccine example.

HPV vaccine-oriented GBA offer a one-dimensional treatment of gender – or, more appropriately women – which harkens back to standard second wave feminist fare when scholars focused on the wide-sweeping subordination of women (Ortner 1974; Rosaldo 1974). While seeking to understand "why sexual asymmetry [is] a universal fact of human societies" (Rosaldo 1974:22), academics developed totalizing theories to address this polemic. Rosaldo posited that women's oppression stemmed from the positive cultural values associated with men's activities in the public sphere of business and politics which were then contrasted with the negative cultural values associated with women's activities in the private sphere of the home (1974:41). Ortner also drew on cultural associations of gender to account for the subjugation of women. Ortner argued rather persuasively, that women's inferior status was linked to her association with nature (mothering, breastfeeding, nurturing, and so on), whereas men were seen as belonging to culture (higher office, business, politics and general spheres of influence, and so on)(1974). Ortner's schema is particularly relevant to one of Merck Frosst's HPV vaccine advertising campaigns, which is directed at mothers. They are told in the advertisements that it is their specific duty to protect their daughters by getting them vaccinated (this campaign and mothers' reactions to it are covered in more detail in Chapter Four). Rosaldo's and Ortner's theories still have saliency today for these gendered cultural associations continue to circulate in medical, pharmaceutical and governmental discourses. But their totalizing of women is problematic. Not all women face subjection in the same way, one's class, age, education, geographic location, race, ethnicity and religion also play a part, as has been explored more exhaustively in more recent feminist anthropology (see Abu-Lughod 2008[1993]; di Leonardo 1998; Scheper-Hughes 1999; Tsing 1993; Visweswaran 1994). This scholarship, which coincides with third-wave feminism, focuses on the intersection of race, class, marginality and gender around the globe. However, as Visweswaran states, "it is not enough to consider race, class, and sexuality as additive categories to a central concept"

(1994:75),[19] the central concept being, of course, gender. All aspects of intersectionality need to be given due consideration. GBA's epistemological focus, which appears to be stuck in a previous analytical era, explains why Aboriginal groups such as the Native Women's Association of Canada have been particularly displeased with GBA. In a 2007 report, the Native Women's Association of Canada declared, "Canada and others who have applied a GBA have failed to do so in a way that is sensitive to the multiple needs of Aboriginal women, who suffer not only from gendered discrimination, but racism and other forms of oppression. For example, Aboriginal two-spirited women also suffer from discrimination based on their sexual orientation and women with disabilities also must deal with discrimination based on disability" (6). The federal government's GBA approach to the HPV vaccine deploys a distilled and vexing conception of gender. While the federal government's motivations may be more benign than that of Merck Frosst's – it is not trying to sell vaccines – GBA is tasked with addressing a universal health disadvantage that women, as a homogenous group, will experience. Thus, all women are at-risk all of the time.

Might we better serve women's health by taking a step back and re-conceiving how the concept of gender is deployed in governmental policy and, as a result, how risk is

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[19] In May 2013, the federal government announced it would be instituting an improved GBA framework called "GBA+". Status of Women Canada explained that "the 'plus' in the name highlights that gender-based analysis goes beyond gender, and includes the examination of a range of other intersecting identity factors (such as age, education, language, geography, culture and income)" (2013:1). While it is too soon to evaluate this initiative, the name and premise calls for pause – it sounds similar to what Visweswaran warned against: keeping gender as the primary axis of analysis while adding on other positionality factors for consideration.

attributed? Weed and Butler (2011) urge just this. In reference to the invocation of GBA by international non-governmental bodies, such as United Nations agencies, Weed and Butler insist that:

> [G]ender is formed in relation to other social and political modes of social organization and is itself actively producing and reproducing such modes, including the family, labor, class, slavery, imperialism, immigration politics, and the state, to name a few . . . . Since gender is not an isolated factor or element on such a map, but is itself mobilized in a constitutive and productive relation to those other modes of organizing political life, the only way to gauge its usefulness is by tracking those effects. [2011:4-5]

In this quotation, Weed and Butler attempt to establish gender as a wide-open concept, not one that is *entirely* pre-determined. To further explain, one must acknowledge that gender "is a practice of improvisation within a scene of constraint. . . . The terms that make up one's gender are, from the start, outside oneself in a sociality that has no single author (and that radically contests the notion of authorship itself)" (Butler 2004:1). The constraint that Butler speaks about is demonstrated by the fact that policy – as well as pharmaceutical marketing campaigns – scripts subject formation[20]. Petryna also notes that policy orders an individual's identity or sense of self and influences how this identity is communicated, interrogated and absorbed into daily life (2002). In the case of the HPV vaccine policy and pharmaceutical marketing strategies, the at-risk girl/woman comes into being. The at-risk girl/woman is firmly put in a Douglas-described box in order to maintain societal order – in short, the gender asymmetrical status quo.

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[20] Giroux (2010) argues that neoliberalism is "also a political project, intent on producing new forms of subjectivity and sanctioning particular modes of conduct" (7-8). Merck Frosst's campaign brings this point into relief.

Conclusion

The purpose of this chapter is to provide a historical, economic and political account of how the HPV vaccine was introduced in Canada. The chapter charted how, through descriptions of the sales/governance strategies employed, Merck Frosst and the federal government set the stage for the Province of Ontario to take up a gendered public health program which offered the HPV vaccine to grade eight girls free of charge. This public health programming hinged on the notion of the HPV-related at-risk girl/woman. As a result of this circulating and gendered at-risk rendering, HPV-related subject formations were created. It is the objective of this research project to assess how this subject formation has been turned into everyday "subjectivities" (Biehl et al. 2007). In other words, how do women mediate, hybridize and reject the at-risk categorization they are subjected to? How do they respond to such one dimensional, static and totalizing renditions of gender – or, more succinctly, scripts of being a woman – that are entrenched in risk discourses? As the next chapter outlines, I interviewed mothers who had daughters at or near the school-based vaccination age of grade eight. But as fieldwork progressed I discovered that official HPV vaccine policy had seeped into other women's lives, and other cohorts of women who were not mothers were also being encouraged to take up the vaccine – university-aged women and women who are being vaccinated against HPV (in my case, women attending a gynecology unit at Sunnybrook hospital and its HPV vaccine clinic). Thus, what was originally a focused research endeavor turned into an exercise in fluid ethnography.

CHAPTER THREE - Gathering Women's Narratives: Lived Experiences of Negotiating Gender and Risk

The worthiest of questions are not at all guaranteed to remain stable through the empirical course of their resolution, and what instability and mutation they exhibit make unstable and liable to mutation every one of their epistemological and ontological fortifications. [Faubion 2009:162]

Introduction

In this chapter methodological approaches used throughout my field research are recounted and I outline my experiences in the field. As indicated in the previous chapter, in the first stage of fieldwork I conducted a three-month archival search in order to answer the first of my three research questions: (1) How did the HPV vaccine become gendered within the Canadian policy landscape, and how did this in turn lead to gendered public health programming? This first phase of field research allowed me to re-shape the parameters of the research project by clarifying the theoretical underpinnings of the research project and in turn I was able to narrow down my two subsequent research questions: (2) How are women appropriating, hybridizing or refuting notions of "gender" and "risk" that are deployed in association with the HPV vaccine? and (3) How are their experiences of risk and gender folded into their vaccine decision making? Armed with these revised research questions, I set out to find people, places and spaces where I could conduct my research. As I quickly discovered, securing an institutional arrangement – meaning a clinical space to conduct participant observation – was a challenge but one that was finally arranged, albeit in a modified form from what I had originally anticipated. In addition, the enthusiastic response I received from women regarding the research, and the discovery of an additional cohort to interview, was most unexpected. Throughout my fieldwork, it was imperative that I remain flexible as approaches and questions were continually being fine-tuned. I discovered that on-the-ground HPV policy also had clinical, as opposed to governmental, impetuses and that HPV infection stories were an integral component of HPV vaccine decision making for many women. I also learned that my findings could solicit strong and emotional responses from academics and interview participants alike. While change (hence uncertainty) can be unnerving, it can also lead to research opportunities never previously anticipated.

A] Research Questions: Preparing for and Delving into the Intersubjective Space

The archival research conducted to trace the introduction of the HPV vaccine in Canada was a critical endeavor in contextualizing women's narratives by tracking the creation and circulation of expert HPV vaccine knowledge, and how this information deploys the concepts of gender and risk to enact sales/governance strategies. In tracing this history, I examined what topics were circulating, and "who does the speaking, the positions and viewpoints from which they speak, the institutions which prompt people to speak about it and which store and distribute the things that are said" (Foucault 1990[1978]:11). I utilized a governmentality frame to elucidate gendered risk-making based on Foucault but updated to include work by Castel (1991), Giroux (2010), Gordon (1991), Lupton and Petersen (1996), Nettleton (1997), Petersen (1997), Rose (2007), Rothstein (2006) and Turner (1997). Through my archival research, the *processes* through which risk categories are created and circulated were highlighted. Furthermore, Douglas's (1992, 2002[1966]) and Lupton's (1994, 1995, 1999a, 1999b, 2003) writings illuminate how this risk making creates a *product*. In this case, this product is the category of the at-risk girl/woman. Thus, a theoretical métissage consisting of governmentality approaches to risk, Douglas's cultural writings on risk and Lupton's more recent work on gender and risk,[21] was assembled to answer the first research question: (1) How did HPV vaccine policy and subsequent public health programming become gendered? The results of the archival research in answer to the first research question were not particularly surprising. Merck Frosst, a multinational pharmaceutical company, led governmental policy, which was predicated on static and one-dimensional portrayals of women.

Invoking alternate risk epistemologies, such as the "global risk society" work of Beck and Willhems (2004) and Giddens (1991) would not have provided the breadth or epistemological foundation to answer this question. While the governmentality perspective emphasizes the role of governance technologies as they are deployed in

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[21] Lupton also fuses governmentality and cultural approaches to risk in her research.

their multiplicity in regard to risk, the risk society approach highlights the embedded nature of risk within modern societies “as a feature of the ontological conditions of humans within current social forms” (Dean 1999:132). Dean explains that Beck’s risk society theory is framed in the “*totalizing* assumption . . . [of] risk” (1999:135, emphasis in original). According to Beck, risk is ubiquitous in the modernization period, affecting all in equal probability, regardless of socio-economic standing. Beck asserts that while situations like “poverty [are] hierarchical, smog is democratic” (2004:130). Such a risk framework does not conceptualize risk as stemming from discrete and calculable incidents, but as phenomena which cannot be “spatially, temporally, and socially bounded” (Beck 2004:115). Giddens offers a similar theory whereby the risks of “high modernity” are considered to be globalized, treacherous and on a scale not seen in pre-modern times (1991:4). While Giddens’s writing is situated within the cold war era (for example, he makes reference to the nuclear arms race), his work predicts further “ecological catastrophe” (as was evidenced by the Chernobyl disaster in the late 1980s) due to scientific “advancement” (1991:4). As such, Giddens views the future as uncertain and this requires all to be “open to contingent happenings” (1991:28). Both Beck and Giddens advance the risk society thesis as a steadfast critique of modernity. Fox posits that Beck also employs the risk society thesis in an effort to mobilize against the injustices of capitalism in the wake of the failure of socialism when the old tenets of class gave way (1997). As a result, there is an increased possibility to organize along new lines. However, regardless of intentionality, even Beck admits that his critique of modernity is incompatible with governmentality approaches to risk. Beck describes Foucault's theories as, "paint[ing] modern society as a technocratic prison of bureaucratic institutions and expert knowledge in which people are mere wheels in the giant machine of technocratic and bureaucratic rationality" (2000:222). Conversely, Beck argues that his risk society thesis is predicated upon continually fluid political structures and management. What Beck misses in his critique is that governmentality approaches to risk emphasize core governance strategies that are tweaked depending upon the context – within a constant there is fluidity. In the case of the HPV vaccine in Canada and Ontario, Merck Frosst is governing in tandem with national and provincial health authorities through the pivotal promotion of self-regulation. While present day governance strategies vis-à-vis women and health differ slightly from a century ago, the product is still the same; the pre-patient at-risk girl/woman remains a mainstay.

However, there were also two other research questions to be addressed. The theoretical approach utilized to answer the first research question was not germane to the second research question: (2) how are women appropriating, hybridizing or refuting the notions of "risk" and "gender" that are deployed in association with the vaccine? In question two, the concept of "risk" is meant to invoke notions of risk as espoused by Fox (1997) and Ewald (1991). Fox discusses how in pre-modern times, the concept of risk did not carry negative connotations, but focused on the potentiality of procuring "losses and gains" (1997:12). Today, Fox argues, risk "has been co-opted as a term reserved for a negative or undesirable outcome, and as such, is synonymous with the terms *danger* or *hazard*" (1997:12). Ewald, perhaps one of the most cited authors regarding definitions of risk, posits that risk "is a category of understanding" (1991:199). Therefore, risk itself is not a loaded concept or event, it is the meaning that is attributed to or affiliated with it in governance strategies that creates the notion of danger or a hazard. Whether it is the insurance industry, which Ewald is writing about, or vaccination policy, governing strategies work to define what is and who is at risk[22]. The notion of "gender" in question two signifies the homogenous and static rendition of women as perpetually at risk for illness and disease, as circulated in Merck Frosst marketing and used in GBA. As Moore explains, "Gender can refer to a set of ideas and images that we recognize as pertaining to, for example, traditional femininity, even if we don't subscribe to the practices those ideas and images entail" (2010:106). As Hankivsky also (2012) argues, this approach to gender pits men against women, views each as undifferentiated "wholes" and places a primacy on the effects of gender on health. The essence of research question two, however, is to understand how governance formulated versions of risk and gender work themselves out on-the-ground in women's daily lives.

As was found with question two, the theory used in the archival research was also not relevant to the third research question: (3) How are women's on-the-ground experiences of "risk" and "gender" folded into their vaccine decision-making? Correspondingly, all

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[22] This use of risk is not meant to propagate Beck's notion of "manufactured uncertainty" (2000:216). Manufactured uncertainty refers to risk that is a product of and a factor inherent to modernity. While Beck argues that he is both a realist and a constructivist (2000:212), his writings veer more to the realist side of the risk equation than governmentality approaches to risk, which emphasize the construction of risk as a governance technique.

three socio-cultural approaches to risk – the cultural, governmentality and risk society frames – operate at a meta-theoretical level. Their epistemologies serve an important purpose, but do not operate on an experiential plane. As Lupton notes, "there remains much room for investigations addressing these issues which bring together theories on risk with empirical research and go beyond the universal 'risk subject' that tends to appear particularly in the 'risk society' and 'governmentality' perspectives" (1999a:6). Additionally, Lupton observes, "the theorization of risk has tended to neglect the insights offered by contemporary feminist theory and the sociology of the body in understanding the links between gender, embodiment, subjectivity and risk" (1999a:7-8).

Nettleton posits that Foucault's later work – which focuses on the development of the self within power structures – brings forth the possibility of researching individuals negotiating risk by exploring their grounded experiences (1997:219). Lupton invokes similar strategies in her research concerning women's health and risk (1997b). In *The History of Sexuality: An Introduction* (1990[1978]), Foucault stresses, "power is everywhere; not because it embraces everything but because it comes from everywhere" (93). Power is both recognizable and not easily identified (Highway 1998). Power is a fluid set of relations that expand, contract, submerge and re-emerge depending upon the context. Power also does not belong to those with institutional rank: "power comes from below; that is, there is no binary and all-encompassing opposition between rulers and ruled" (Foucault 1990[1978]:94).

By examining Foucault's work in its breadth, the construction of subjects within the frameworks of power relations is acknowledged, but also the possibility of such subjects to level their own limited, and often momentary, "critique" while enmeshed in these very power networks (Allen 2008:21). As Allen, who also brings a feminist perspective to the conversation, explains "power works at the intrasubjective level to shape and constitute our very subjectivity, *and* an account of autonomy that captures the constituted subject's capacity for critical reflection and self-transformation, its capacity to be self-constituting" (2008:2-3). Importantly, women's narratives provide the intersubjective space where subject formation and realizations/actualizations of the self intersect. It is precisely in this intersubjective space that health negotiation and decision making occur. In the intersubjective space, women work towards becoming ethical beings (Foucault 1997). This process involves continually engaging in acts of self-reflexivity or "practices of the self" to achieve one's goals of the good or moral (Butler 2008:27-28). When referring to being ethical, Foucault is foundationally speaking of engaging in a relationship with oneself in which we create our own telos, which is our own code or sets of codes for daily life (Foucault 1997). Scripting one's telos "is nevertheless not something the individual invents by himself. They are patterns that he finds in his culture and which are proposed, suggested and by his culture, his society and his social group" (Foucault 1987:11)[23]. As a result, in the era of new public health

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[23] Foucault's use of the male gender only is problematic in this quote and his work overall. Theory has also been drawn from Allen (2008), Butler (2008), Douglas (1992,

creating one's own telos can function as forms of "self-surveillance" whereby individuals are constantly and actively enacting health measures to keep themselves well and away from anticipated risk (Nettleton 1996:43). Moore also notes that, "the new paradigm of health is a deeply gendered project, and without such an acknowledgment we forgo an understanding of health promotion as an 'operation of power' that is rooted in gender norms" (2010:103). Therefore, in scripting one's own telos, one is engaging in "ethical agency" (Butler 2008:28) or what Allen called one's ability to be "self-constituting" (2008:2). These actions are, nevertheless, predicated upon normative understandings of gender, even if these understandings can be temporarily destabilized or re-ordered.

Beck and Giddens also address the self in their work. However, they posit that individuals posses an autonomous and rational ego which integrates knowledge to administer their lives on a quotidian basis within the risk society environment. For Giddens, this knowledge is based upon the process of "self-therapy" through which one constantly self-evaluates and self-administers solutions in the quest for a more fulfilling life (1991:70-108). For Beck, self-orientated action is encapsulated in his concept of "disembedded individualization" (2004:63). This involves being in charge of your own personal narrative as prescribed roles along the lines of class, ethnicity or race, which are synonymous with the period of first modernity, are no longer tenable. Beck

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2002[1966]), Lupton (1997a, 1997b), Moore (2010) and Nettleton (1996, 1997) in order to incorporate a feminist lens into the analysis.

suggests that “under these conditions, individual agency now assumes a central place” (2004:65).

Giddens and Beck base their conceptualizations of the self on a person “actively engaged in shaping his or her own biography and making decisions according to calculations of risk and opportunity” (Petersen 1997:192). This treatment of the self is a classic modernist tale, one which is subtly focused on “a meta-narrative of progress and evolving self-consciousness” (Petersen 1997:191). This rendering of the self runs in opposition to views of the self in governmentality approaches to risk and Foucault’s later work.[24] Neither Foucault, nor those who have updated Foucault’s theories like Castel (1991), Giroux (2010), Gordon (1991), Lupton and Petersen (1996), Nettleton (1997), Petersen (1997), Rose (2007), Rothstein 2006 and Turner (1997), claim that one has control over one’s sense of self. Instead, individuals are always operating within the structures and parameters of power, as detailed by Butler (2008). Thus, to answer research questions two and three – in short, to understand how the intersubjective “space” functions – I set out to map women’s lived experiences of negotiating gender and risk in relation to the HPV vaccine by drawing theoretical inspiration from Foucault’s late writings (1987, 1990[1978], 1997), Allen (2008), Butler (2008), Nettleton (1997) and Lupton (1997b). The spirit of Zaloom’s (2004) work has also

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[24] While Beck’s and Giddens’s risk society theories do not provide an appropriate theoretical template to answer questions two and three, the themes of trust and fatalism have been lifted from their work to assist in illuminating vaccine decision making by students and patients. The themes of trust and fatalism are not central epistemological tenets of Beck’s and Giddens’s writings.

been threaded throughout data analysis to answer questions two and three. Zaloom posits that risk can, indeed, be a productive force vis-à-vis one's sense of self in one's daily experiences. Risk is "practiced" (Zaloom 2004:368), a concept akin to Butler's treatment of gender.

Before recounting methodological strategies it is imperative, however, to define what is meant by experiences. As Scott states, "what counts as experience is neither self-evident or straightforward; it is always contested, always therefore political" (1992:37).[25] By experiences, I am referring to delving into and magnifying subjectivities as they are continually developing. It is important to note that the concept of subjectivities is used in its plural form, denoting multiple incarnations. The research project does not seek to make women visible in the sense that *the* missing female voice must be added to the archive (Foucault 1999) or the "anti-archive" (Hughes 2003:28), even though such an approach would be popular amongst feminist health activists who overlook difference in order to "provide the basis for a collective feminist subject" (Sawicki 1991:8-17). My politics lie elsewhere for I concur with Scott, who states that "the project of making experience visible precludes analysis of this system and its historicity; instead it reproduces its terms" (1992:25). I do not want to fall into the very trap that Douglas (1992) describes – reinforcing the current social "order".[26] In carrying out this

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[25] The approach taken throughout my fieldwork was also political, underscored by the theoretical underpinnings of the research project.

[26] As an example of such an approach and results, Scott discusses E.P. Thompson's work. In looking to contest the closed nature of the category of "class," Thompson positioned experience as a state of "social being – the lived realities of social life"

research, there is the danger of re-producing essentialized notions of gender and risk; researching women only while critiquing GBA as it is deployed in pharmaceutical and governmental discourses which place a primacy on women as a homogenous, static and universalized at-risk group could be a recipe for certain critical failure. I explicitly avoid unintentionally re-producing the products of power techniques. Through the archival research, I trace the social, political, cultural and economic locations of HPV vaccine-related gendered-risk making in pharmaceutical and governmental discourses. This allows me to situate this specific subject formation at a particular point in time. This "historicizing" (Scott 1992:26) is crucial in establishing the constructedness of gendered risk as a conceptual category. I also seek to unearth how these concepts of gender and risk travel in the social realm between, across and within different groups of women. If experience is "a subject's history" (Scott 1992:34), it is important to provide a critical account of these histories. In doing so, however, it is paramount not to, "mask . . . the necessarily discursive character of these experiences" (Scott 1992:31). Women hold multiple positionalities through which they develop and re-work their sense of self and identity. Race, class, age, sexual orientation, occupation, medical status and religion are all intersectional positions on the identity continuum (Inhorn 2006). However, at the same time, "it would be wrong to assume in advance that there is a category of 'women' that simply needs to be filled in with various components of race, class, age, ethnicity, and sexuality in order to become complete" (Butler

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(quoted in Scott 1992:29). While this take on experience does allow for agentive aspects of experience to emerge, Thompson's analysis rests firmly upon the affects/effects of the "relations of production", thereby re-affirming class as a "unifying phenomenon, overriding other kinds of diversity" (Scott 1992:29).

2007[1990]:20). This is a tricky line to navigate and efforts to be mindful of these issues guided the fieldwork process. As such, a fluid approach to fieldwork and ethnography was imperative.

As it turns out, immersing myself in the field (Kendall 1999; Kent 1992; Pratt 1986), in combination with being in the right place at the right time, provided the insight and contacts to productively widen the scope of the research project. As a result, I was able to track women who were at different stages in the lifecycle with diverse HPV vaccine-related experiences and stories. Perhaps being in the right place at the right time is more than just presenting oneself in a particular milieu. Being flexible also means being attuned to moments of change and ambiguity throughout the research process; being cognizant of moving currents on-the-ground allows you to place yourself within "implosions" (Martin 1994:11). As Martin states, while drawing on Baudrillard, fieldwork has the potential to "fetch . . . [you] up in what has been called *implosions*, places where different elements of the system come into energetic contact and collapse in on themselves" (1994:11). This only happens if one is present while in the field and paying attention.

B] Shifting Research Parameters

In carrying out a flexible approach to the research project, I took a cue from Martin's ethnographic approach in *Flexible Bodies*: *Tracking Immunity in American Culture*

From the Days of Polio to the Days of AIDS (1994). In her book, Martin tracks the metaphor of the human body, health and the immune system in the 20th century through the popular press, on the street and in science laboratories. Following the concepts of gender and risk as they are deployed in GBA policy requires an equally creative approach: I interviewed university women, mothers and patients at a hospital clinic. Not surprisingly, each cohort is associated with an institution that has historically regulated women: schools, homes and hospitals. A fluid approach to ethnography also requires a "reconceptualization of 'the field'; not as a discrete local community or bounded geographical area, but as a social and political space articulated through relations of power and systems of governance" (Shore and Wright 1997:14). Wedel et al. (2005) similarly describe the field as "often consist[ing] of loosely connected actors with varying degrees of institutional leverage located in multiple 'sites' that are not always even geographically fixed" (39). Thus, for the purposes of this research project, the concept of the field is widely framed and steers clear of anchoring premises, including cohesively bounded social groupings (Metcalf 2001). The women interviewed lived throughout the Greater Toronto Area in many domestic arrangements and the students were dispersed across the province in large and small universities and pursued a plethora of educational avenues. Although all patients attended the same hospital clinic, it is hard to characterize patients as members of a particular community. Plant posits that community is often used as a measure to judge "what society ought to be like" (1974:14) and along with this assumption comes the premise that all members share cohesive needs, thus requiring the same types of health services (Jewkes and Murcott

1996). As research at the clinic revealed, it did not appear as though patients knew one another outside the clinic for they rarely ever spoke to one another while presenting for their shots and certainly did not sit together in the waiting room. This broadened approach to the field is becoming more common in anthropology today. As Marcus states, "fieldwork projects in anthropology are not what they used to be" (2009:1).[27] The research project also did not entail the traditional going away to a field – I forwent an anthropological rite of passage by doing research where I live, at home. I did not find this to be problematic as a feminist researcher because "conquering the field far away" (Sparke 1996) has unnecessarily sexist undertones, which is a methodological approach I wished to avoid.

My initial intention was not to interview mothers, students and patients. To answer my research questions, I originally planned to interview women who were being targeted by HPV-related government policy and Merck Frosst's marketing campaigns. I assumed that this approach would lead me to two obvious groups of women – mothers of grade eight-aged girls and university students. In beginning the interview process, in fact, I only set out to interview the first group, as they were the targets of the only HPV vaccine policy in the province. I was familiar with the grade eight vaccination program because such a program is held yearly at my children's school and mothers in the various communities I claim membership in are abuzz with it. It made sense to

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[27] However, the anthropological discipline as a whole is reluctant to talk about the myriad of ways in which fieldwork is *actually* carried out for fear of disturbing the discipline's brand; what does not "resemble the classic mise-en-scène of fieldwork" à la Malinowsky is often brushed under the carpet (Marcus 2009:4).

interview mothers who were being targeted so specifically and clearly to get their daughters vaccinated. Once I passed my proposal defense and received ethics clearance from York University (see letter in Appendix B), I did just that.

I was also made aware of the Merck Frosst campaign targeting university-aged women by the large advertisements hanging in the student centre at York University and the many smaller Gardasil® advertisements that were posted outside the campus health clinic and pharmacy, and also in the student centre. It did not occur to me to interview women students until students of my own, like Sylvana, asked to be interviewed. While talking to my students before, during and after class, I discovered that campus health clinic physicians were actively promoting the vaccine to women students when they visited clinics, no matter the reason for the visit. Students would often mention that they went into the clinic because of a cold or the flu and would come out with a prescription for the vaccine. Thus, it became clear that students were the targets of a clinical HPV vaccine policy. While not specifically governmental (although clearly a spillover from official provincial policy), similar policies, as research with university students would reveal, were being implemented across the province. I had to, therefore, re-assess how I conceptualized the term "policy." As such, for the purposes of this research project "policy" is defined as not only "a piece of government legislation . . . [but] a general program or desired state of affairs or, alternatively, as a label to describe outcomes or what governments generally achieve" (Wedel et al. 2005:35).

Unearthing the student cohort was another pivotal point in the fieldwork process for students brought into relief how prevalent HPV infection actually is. As unexpected as the presentation of this cohort was, it was a prescient primer for patient interviews which followed, as students' HPV stories would foreshadow patient HPV diagnoses and treatment stories, which outline how patients work to contain, rather than prevent protracted HPV infections.

C] Doors Closed, Doors Opened

While I was undertaking the archival research to answer the first research question, I began looking for a clinic where I could engage in the more traditional practice of participant observation. The first place I turned to was a school-based vaccine clinic. These clinics were mobile and set up in school gyms and lunchrooms across the province. Unfortunately the local health authority refused my request to observe its vaccination program in action. The authority pointed out that participant observation would present an ethical quagmire for them as everyone present would have to consent, including nurses, teachers, students, parents and this would be too cumbersome a process to carry out. I could understand their concern regarding participant observation as the school-based clinics were busy and there was no control as to who walked in and out. I had read about the difficulty medical anthropologists have in securing participant observation rights in clinical settings because of the increasingly tightening patient privacy laws (see Martin 2009), so I was not surprised with their decision to decline my request. I had also been worried that in order to observe the mobile clinics I would have to get ethics clearance from the school board, in addition to the public health authority.

My second attempt to find a clinical site went much more smoothly. After having found information on the Internet about a hospital-based HPV vaccine clinic at Sunnybrook Hospital in Toronto, I decided to find out more about their program. I was not sure if my request would be granted, but figured there was nothing to lose by placing a call. To my pleasant surprise the nurse practitioner who ran the clinic phoned back in a timely manner. Not only was she encouraging about the research project, she took the time to explain that many of their patients were not under 26 as I had understood from initial research.[28] The nurse practitioner explained that there was a clause in the 2007 NACI statement which allowed the vaccine to be administered to older women at their physician's discretion. As a result, women older than 26 who attended the hospital's colposcopy clinic were also getting the vaccine when recommended by the attending gynecologist. I had unearthed a second clinical HPV vaccine policy. Hospital gynecologists were recommending the vaccine to patients with protracted HPV infections resulting in cervical dysplasia to protect them from future infection of HPV strains they had not yet been exposed to.

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[28] I had thought the women attending the clinic would be under 26 because at this point in time Gardasil® was approved for use in women 26 years of age or younger, although this was amended to include women up to the age of 45 a few years later, as is outlined in the previous chapter.

The nurse practitioner gave me the name and contact details of the physician in charge of the vaccine clinic and suggested I approach her directly regarding my research request. I then prepared a research project summary, a list of interview questions and an updated CV, which I sent to the physician who oversaw the clinic. The physician responded the same day saying that she would be happy to sponsor my research in the HPV vaccine clinic. She explained that I needed to submit my research project information to Sunnybrook's Women and Babies Departmental Research Oversight Committee for pre-approval before I could submit the research request to the hospital's overarching Ethics Review Board. The Women and Babies Departmental Research Oversight Committee approved the request except for the participant observation component. The rationale for not approving the participant observation again came down to patient privacy. As the vaccine clinic was not held in a dedicated space, meaning that an entire Gynecology Department functioned out of the same area of the hospital, it was impossible to obtain adequate consent. There was not a single dedicated room for vaccination; the clinic nurse moved between different types of rooms – exam rooms to medical procedure rooms – in order to administer the vaccine. It could be argued that it might have been appropriate to follow the nurse practitioner around as she tended to patients, but this was not an option, as it was not approved. All gynecology patients, including new mothers and those being diagnosed with gynecological cancer, used the same busy waiting room. It did not make sense to observe patients in the waiting room who were at the hospital for entirely different purposes. I was, of course, disappointed with the limitations of the approval, but moved forward with the remaining components of the project.

All of this being said, I did have plenty of opportunity to observe while I attended the hospital clinic as I was posted at the nursing station each week. Being at the clinic provided me with the knowledge of how the clinic functioned, exposing me to the busy nature of the gynecology floor, the enormous stress placed on medical professionals, nurses and physicians alike, how patients interacted with them, and the families or friends patients brought with them as support while signing in and out of the clinic. I was also fortunate to watch the clinic in action in two very different hospital environments. When I started my research in June, 2010, the Sunnybrook clinic was housed at Women's College Hospital (WCH). WCH is a much smaller hospital than Sunnybrook's main campus and provided a more intimate clinic setting. In September, 2010, when the Sunnybrook main campus renovation was complete, I transferred my research to the large, new building when the Women and Babies Department moved. As this was an entirely new building, all spaces had up-to-date furniture and equipment and the Women and Babies floor was at least four times larger than the clinic had been at WCH. While the clinic at WCH had been busy, the environment at the new Sunnybrook building was dizzyingly fast-paced. The much larger floor meant that a multitude of gynecology related departments were functioning out of the same space. While I could not write about these observations, as no ethics permission was granted, being there augmented my understanding of the HPV vaccination experience within a hospital environment. However, my use of the phrase "being there" is not to be construed as "I know because I have been there" which is then translated into "grounds for authority" (Moore 1994:2-9). I posit simply that by being there my interviews were richer and my analysis was more nuanced than it would have been if I had not been present in the clinic environment.

The interview component of fieldwork research focused upon gathering narratives, a long-standing tradition in medical anthropology (see Kleinman 1988). Narratives are ideal for situating analyses of how women are appropriating, hybridizing or refuting the notions of "gender" and "risk" as they are deployed in HPV vaccine related policy – whether governmental or clinical – for:

> Text, textuality, derived from *texto* (Latin, to weave), constitutes the locus where bodies discursive and material weave fabrics of the self. The body of each text contains two other bodies which shape the text as it shapes them: the physical body and the body politic whose materiality the physical body symbolically represents. [Smith-Rosenburg 1989:102]

However, as Butler notes, narrative snapshots usually begin in the middle, and accounts are "partial, haunted by that for which I can devise no definitive story. I cannot explain exactly why I have emerged in this way, and my efforts at narrative reconstruction are always undergoing revision. There is that in me and of me for which I can give no account" (2008:37). Biehl et al. (2007) also stress that "subjects are themselves unfinished and unfinishable" (15). As a result there is always a feeling of "incompleteness" (Marcus 2009:28) when engaging in narrative research and analysis.

Thus, I only claim to capture women while they inhabit the intersubjective space at a specific point in time in their lives. Their rationales and recountings are bound to change and take different directions at other times.

Once approval from the Women and Babies Department was received to proceed, I began filling out the many forms required to make a formal research request to Sunnybrook's Research Ethics Board (see Appendix C). After completing the forms, I brought them to York University's Faculty of Graduate Studies (FGS) for review and signature. After reviewing the application, FGS decided they would only sign them after Sunnybrook's Research Ethics Board approved the project. I then took the forms to Sunnybrook and submitted the project for approval. Unfortunately, the approval was delayed by the hospital for a few months because the reviewer was out of the country. It was finally approved by the hospital on April 23, 2010, after I agreed to make a slight adjustment in how data was to be stored (see Appendix D).

In terms of a timeline, I first called the HPV clinic in September 2009 and the project was approved seven months later. However, this was not the only delay I encountered. Once I received hospital approval, a data transfer agreement (DTA) had to be signed by York University and Sunnybrook. York University was concerned about signing the DTA on my behalf because of liability issues as I was not an employee of the university. It appeared as though I was the first graduate student who had unilaterally negotiated a research arrangement with a hospital. Typically, this is done through a supervisor because graduate student requests to conduct research at hospitals are often lab related. Finally, in June 2010, after my supervisor, as an employee of York University, signed the DTA on my behalf, I was able to return the DTA to Sunnybrook to be approved. As a result, I started research work at the clinic in June, ten months after initial contact with the hospital.

D] Gathering Women's Narratives

While creating an interview schedule, I was careful to ensure the breadth needed to allow the complexity of women's responses to medicalization to emerge. Interview questions covered such topics as perspectives on cancer causation; cervical cancer etiology; experiences with Pap tests, HPV infection and related medical procedures; Ontario government policy of inoculating grade eight girls; gendered aspects of the vaccine and virus; and how best to implement HPV-related public health initiatives in the future. Interview questions were crafted to unearth how women were processing, hybridizing or refuting notions of "gender" and "risk" as they were currently deployed in pharmaceutical and governmental discourses in Ontario. The central objective of the interview questions was to understand how health decisions were made in the intersubjective space (see Appendix E for the interview schedule).

While drafting the interview schedule, I was aware of how my positionality was affecting the questions I asked, how I asked them and to whom I asked them. My positionality influenced the knowledge produced in this research and my experiences filtered how I gathered and analyzed other women's experiences. Throughout my fieldwork I had to work to open up the apertures of my lenses – that of a white, married, middle-class academic with two children at home. My experiences, of course, did not necessarily reflect those of the women interviewed and their histories did not always mirror mine. My narrative and those of the women I interviewed sometimes intertwined and, at other junctures, moved in different directions (Keniston 2004:233). Having membership in multiple mother and student communities made me a "connected critic" (Bourgeault and MacDonald 2000:153) and as I will discuss towards the end of the chapter, also accountable, to a certain extent, for my research findings. However, before I discuss data analysis, I will outline the recruitment strategies I used for each cohort and the demographic diversity found within and between each cohort of women interviewees (see Appendix F).

1. Mothers

The women interviewed for Chapter Four all had daughters at, near or just past the grade eight age and reside in Toronto or its environs. This was quite a diverse cohort in terms of occupation, but not of race or class, as all the women were white and middle class. As a baseline, all the women were middle class homeowners, however a few would be considered upper-middle class. All mothers had achieved an undergraduate degree and some held advanced degrees.[29] Some mothers worked full-time outside the home, some worked full-time in home-based businesses, some part-time outside the home and some were raising their children full-time. Mothers were married, divorced or never married. In terms of professions, mothers were engineers, entrepreneurs, journalists, professors, business executives and health care professionals. A few mothers had disabilities in the form of mild anxiety disorders. In terms of religious affiliation, women ranged from having none to being faithful Christian church attendees.[30] Most interviews were conducted in person with the mothers around kitchen tables, in coffee shops near their homes and at their offices. A few interviews were held over the telephone because of the distance between myself and the interviewee or a special circumstance (for example, one mother was on bed rest due to pregnancy-related complications).

Recruitment was swift and fairly easy as I approached mothers in my own networks (see Appendix G for mother and student consent form). Many participants were kind enough to suggest friends and relatives, who were, most often, happy to participate. My positionality as a mother of two boys at a school offering the vaccine no doubt facilitated recruitment. Mothers would ask me if I thought they should get their children vaccinated at our children's soccer games or when I volunteered in the school

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[29] This is a high educational attainment rate when compared to Canada overall. In 2007 just under 25 percent of Canadians held a university degree (Conference Board of Canada, Education Skills – University Completion 2010:2).

[30] I did not, however, have the opportunity to interview lesbian mothers. I did send out a call for interviewees to various organizations where this participation would seem more likely, but I received no responses.

library for a lunch-time reading program. One mother even invited me out for coffee for the sole purpose of soliciting as much information as she could about the vaccine.

2. Students

Students were an unexpected cohort. Sylvana, introduced in Chapter One, was a student of mine who insisted that I interview her because she *had* to tell me her "HPV story." Once the term ended and I had finalized and submitted the marks, I applied to the York University Ethics Office for an amendment to interview university students. This amendment was granted (Appendix H) and I was finally able to interview Sylvana. She had followed up her initial request by e-mail after the course finished to offer her HPV story again and I was relieved that I could finally accept her request. I did not, however, wish to rely on my own students to fill up this interview cohort. I knew from conversations with other students that HPV infection was common in their age group,[31] so I put out a call for interviewees on a few departmental and club listservs at York University to widen the recruitment net. I received a healthy response. I arranged to interview these students on campus. All students who contacted me for an interview kept their appointment. When I was conducting my interviews with York University

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[31] As an aside, in 2013 as I am writing this, students at another university are still approaching me after class to talk about their HPV infection experiences and offering to help with my research. When I tell them that my research project is complete, they generally look a bit disappointed, but swiftly move to recounting their diagnoses, doctor appointments and related procedures. These conversations still leave me with the impression that the "culture of silence" surrounding HPV infection that I write about in upcoming chapters persists.

students, they would often mention friends and siblings who had similar HPV stories. As a result, mid-way through my York University student interviews, I posted a call for interviewees on a national, feminist listserv, which is populated by academics, policy-makers and non-profit managers/executives. Here again, I received a positive response for interviews. As it turned out, several Canadian women's studies professors posted my call for interviewees on their internal, departmental listservs. This resulted in students from across the province contacting me (see the ethics extension letter in Appendix I). I had to make the difficult decision not to accept more interviewees by mid-summer 2010 and I capped the number of students I interviewed at 24.

All students interviewed were in the process of earning undergraduate, graduate or professional degrees. Student areas of specialization varied from women's studies to law to kinesiology. I did notice that many students were students in health-related fields, particularly nursing. In terms of age, students ranged from the early to late 20s. Just under half of the students were in relationships, engaged or married. This cohort was slightly more ethnically diverse than mothers, with a handful self-describing as being of Asian and Afro-Caribbean descent.[32]

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[32] Despite efforts to recruit non-heterosexual students, I was not successful in this regard. I did send out a call for participants to an LGBT student group, but despite the enthusiasm for my project displayed by the group's director, I did not receive any responses through this recruitment avenue.

3. Patients

After receiving approval from Sunnybrook's Research Ethics Board, I interviewed 20 women seeking HPV inoculations at Sunnybrook's HPV vaccine clinic from June 2010 to December 2010. Arranging interviews necessitated that I attend Wednesday afternoon HPV vaccine clinics in order to firm up telephone interview times or to conduct interviews on site. The nurse practitioner in charge of the clinic handled recruitment and consent as per hospital research protocol. Recruitment posters were placed in examining rooms at the Women's College Hospital (WCH) location of the Sunnybrook clinic. (See Appendix J for a copy of the recruitment poster, which was approved by Sunnybrook's communications department.) Most interviewees explained that it was the recruitment chat with the nurse practitioner that piqued their interest in participating in the study. I provided the nurse practitioner with a recruitment letter (Appendix K), but it was her passion for women's health that encouraged patients to participate. The nurse practitioner also explained the parameters of informed consent to participating patients and oversaw the signing of the form (Appendix L). Patient interest in participating in the study was steady, although more patients signed consent forms than participated in interviews. Not all patients who expressed interest in the study followed through with their set interviews.

In terms of maintaining confidentiality of interviewees and interview data, Sunnybrook confidentiality procedures were followed. A key file, attributing a unique study identifier to each participant, was created. This key file resides at Sunnybrook only, on a secure Sunnybrook server. Research data (including audiotapes and transcriptions of the interviews) with unique study numbers and no identifiable information or personal health information is kept on an encrypted laptop.[33]

Regarding participant demographics, just over half of the patients self-described as single during interviews, by which they meant they were not in a relationship. Most of the remaining patients said they were in long-term, sexually monogamous relationships or in casual relationships, which were not sexually exclusive. One patient was married with a child and one divorced without children. Thus, patients at the clinic were, primarily, not married or in common law relationships without children. These categories are derived from descriptions provided by interviewees; I did not set the parameters within which interviewees described the status of their relationships. As with each other cohort, there was an absence of women who self-identified as lesbian or another non-heterosexual orientation in the patient interview group. Most patients were in their late twenties to mid-thirties, with three patients aged 40. That patients were, for the most part, over 26 years of age is significant, as popular discourse – particularly in the Canadian- and Ontario-based mass media – does not focus on the occurrence of HPV infection in this age group. Nor has much attention been paid to this cohort

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[33] This laptop is encrypted with PGP Whole Disk Encryption, which uses AES 256-bit keys algorithm. Backup copies of the data, in paper form, are kept in a locked filing cabinet in my home to allow me to analyze the data. All data is void of any identifiable information or personal health information, as the interview questionnaire did not solicit such information. Electronic and hard copies of interview transcripts were also given to the nurse practitioner and reside in a secure location at Sunnybrook, apart from the key file.

amongst social science academics studying HPV infection and the vaccine, as current literature tends to focus mainly upon parental decision-making regarding young girls (see Dempsey et al. 2006; Lazcano-Ponze et al. 2001; Ogilvie et al. 2007) and the vaccine and minority health (Fernandez et al. 2009; Livingston et al. 2010; Luque et al. 2011; Luque et al. 2010; Pitts et al. 2009).

In terms of occupational history, patients were employed in solidly middle-class jobs. Patients worked as nurses, occupational therapists, dieticians, accountants, account executives and journalists. As these careers require tertiary education, it was not surprising that interviewees had attended university or college (and in some cases both) and all but one had graduated from a post-secondary institution. Nevertheless, it is important to note that identity categories are complex. Given the high cost of the vaccine (it runs at $160 per dose to total $480 for three shots [SHSC 2007]), these patient demographics were to be expected, particularly in terms of educational attainment and professionally-oriented employment . However, during interviews it became clear that almost half the patients had difficultly putting aside money in their budgets for the vaccine; vaccine cost was a concern for them because many did not have private health insurance. About half had saved the money as they felt the vaccine was worth a try, even if they had already experienced HPV infection and HPV-related interventions to remove abnormal cells. The remaining half of the patients had private health insurance, which covered all or a portion of the vaccine costs. Patients were the only cohort who addressed the cost of the vaccine. This can be explained by virtue of the fact that mothers were deciding upon a fully paid vaccine and that students, by and large, opted not to vaccinate, so cost was not an overriding concern.

I interviewed patients in whichever room was free at the time they agreed to be interviewed. This meant that I conducted interviews in a supply room, examination rooms and the room where the vaccine was administered which housed the vaccine fridge. Some patients opted to be interviewed over the phone as these patients visited the clinic on their lunch hour and needed to get straight back to work after their shot. When I spoke to patients over the phone some chose to be interviewed in a quiet space, while others spoke to me on their cell phones while going about their daily routines.

E] Participatory Analysis

1. Thematic Mapping

Interview data was reviewed through a “categorical-content” type of narrative analysis (Lieblich et al. 1998:13). Lieblich et al. note that categorical-content narrative analysis can also be referred to as “content analysis” – a process through which “categories of the studied topic are defined, and separate utterances of the text are extracted, classified, and gathered into these categories/groups” (1998:13). I focused more on data in the narratives than linguistic structures. While this analytical approach may sound rigid, the methodology takes into account the overarching narrative before identifying common themes and categories, which are formed organically from the narratives, not in a pre-determined fashion (Lieblich et al. 1998:112-3). Categorical-content analysis is a technique particularly suited for examining narratives concerning “agency” and “self-mastery” (Lieblich et al. 1998:17). Transcribing interviews, while a tedious task, forced me to immerse myself in the data. While transcribing I sifted through women’s narratives looking for their discussions on the concepts of “gender” and “risk”. Once the data was isolated and coded (Shoveller et al. 2010), I looked for the most common themes. These varied by cohort, and sometimes within a cohort. When coding it is important to seek out “recurring, converging and contradictory ideas/codes within the interview data” (Shoveller et al. 2010:60). I then thematically mapped the data within and between cohorts. Diagrams of this conceptual mapping can be found in Chapter Seven. Visualizing how each cohort conceptualized, played with, rejected, processed and appropriated the concepts of “gender” and “risk,” along with how they worked through secondary themes such as stigma, HPV infection, “containing” HPV, pre-cancer, etc. not only assisted in organizing each data chapter, it was also helpful in pulling all thematic threads together to provide an overarching analysis, which is outlined in Chapter Seven. Such analysis is a process and not one that garners quick results. In part, analysis took so long because I had to sift through nearly 70 interviews. That in and of itself is an arduous task. But also because I chose to informally test my analysis with participants whenever I could through conference and workshop presentations, and because I formally worked with Sunnybrook staff to elicit their feedback. I prepared a separate research report for the nurse practitioner who ran the clinic and the presiding physician. Both reviewed the report and made only a few minor recommendations regarding my use of medical terms. They were pleased with my analysis and said that the report "really captured" how women experienced HPV infection and related medical procedures. The report was then forwarded to the head of nursing at the hospital.

2. When They Hear What You Say

"When they hear what you say" is a play on words of the title of the edited volume, *When They Read What We Write: The Politics of Ethnography* (1993). Each chapter in this volume outlines experiences of anthropologists who have had their research interpreted and received in ways they did not intend or necessarily anticipate. For example, in conveying her research among pro-life and pro-choice activists in the United States, Ginsberg (1993) recounts how fellow academics interpreted her research to mean that she was sympathetic to right wing, right-to-life causes, a viewpoint not usually accepted among feminist social scientists. Her response was to experiment with her ethnographic writing by juxtaposing her voice with those interviewed in order to differentiate who was saying what. As Ginsburg states, "I could not let my voice stand for my subjects" (1993:174). This may not seem like an experimental turn now, but at the time it was a novel approach to a complex problem.

I shared a similar experience to Ginsburg's on one occasion. While I was working on my data analysis, I ventured onto the Canadian social sciences conference circuit for two years. While response to my research was routinely positive – my presentations generally tended to dominate post-paper question and answer sessions due to the topicality of my research – there is one particular incident that stands out. At the end of my presentation a prominent Canadian feminist scholar yelled at me. She screamed that I betrayed women by supporting the vaccine. I had, in fact, not supported the vaccine in my paper, but presented the varying views women discussed when talking to me about the vaccine. It seemed as though my failure to present a unified feminist subject (Sawicki 1991) vis-à-vis the vaccine created a problem for her; I did not present data to support her feminist activism against the vaccine. I was frustrated as she had missed my argument entirely; I was critiquing the proposition of a homogenous, static and one-dimensional grouping of women that was propagated through GBA-based marketing and policy making. A graduate student I had interviewed was at the same conference presentation. She approached me afterwards and said that I had really captured how she felt about the vaccine. She said that I "got it right." This buoyed my spirits, but the heated exchange was not a pleasant experience. Nevertheless, being accountable to research participants makes one sensitive to how analyses are framed, but also keeps one mindful that research really does matter, both inside and outside the academy.

Conclusion

My fieldwork experience was protracted, full of ethics approval challenges and there was a need to stay attuned to developments on the ground as the HPV vaccine landscape in Ontario was continually shifting. Listening to local-level currents and being flexible in my approach allowed me to interview new groups of women that I could not have anticipated in my pre-fieldwork research project planning. This turned out to be a very good thing. Being immersed in multiple communities of women as part of my daily living as a mother and a graduate student, along with the research privileges I was granted at Sunnybrook Hospital, allowed me to not only delve into how women negotiated the concepts of “gender” and “risk” in HPV vaccine decision making, but to have the opportunity to listen to their HPV stories as well. As it turned out, for students and patients HPV infection and pre-cancer were a significant part of their HPV vaccine negotiation experience.

CHAPTER FOUR - "To Vaccinate or Not to Vaccinate?": Mothers Negotiating HPV Vaccination Decision Making for Daughters in School-based Immunization Programs

What fabrications they are, mothers. Scarecrows, wax dolls for us to stick pins into, crude diagrams. We deny them an existence of their own, we make them up to suit ourselves – our own hungers, our own wishes, our own deficiencies. Now that I have been one myself, I know. [Atwood 2001:116]

[T]he modern image of a good mother – the full-time, stay-at-home mother, isolated in the private sphere and financially dependent on her husband – came as a result of industrialization that took work out of the home and repositioned the domestic space, at least among the middle class, as an exclusively nonproductive and private realm, separate from the public sphere of work. In the Victorian period that followed industrialization, the ideology of moral motherhood that saw mothers as naturally pure, pious, and chaste emerged as the dominant discourse of motherhood. [O'Reilly 2004a:5]

Introduction

Having the responsibility of making health decisions for your child – whether a daughter or a son – is a heavy proposition. As a result, mothers I interviewed exhibited anxiety, strong emotions (both in terms of enthusiasm and disdain) and uncertainty regarding their HPV vaccine decision making. The stress of HPV vaccine decision making was exacerbated by the relatively short period of time they had to make a decision. Schools usually gave two to four days to complete and submit vaccine permission forms. With such a rushed timeframe, few mothers came out of the experience fully confident in their decision. There was always an element of "what if?" that lingered after the process and hence showed up in the interviews. Mothers who opted not to have their daughters vaccinated asked themselves what would happen in the long-term. Would their daughters eventually get cervical cancer? Mothers who opted to have their daughters vaccinated worried about potential long-term side effects of the vaccine. As Carmen, who is prominently featured in this chapter said, "It's a catch -22." Mothers could not see a clear-cut, win-win decision.

While decisions varied, mothers took similar paths in the decision-making process. All mothers researched the vaccine extensively and talked to other mothers, friends and physicians at length about the vaccine. Some did talk to their daughters about the vaccine, but few ventured as far as to frame the discussion in terms of sexual health. Instead, they stayed safely within the cocoon of the actual vaccination discussion and, mostly, avoided broaching sex and sexual relations altogether. While mothers consulted widely regarding vaccine decision making, their decision making ultimately rested within the realm of personal experience – it was not simply a linear, risk/benefit equation. If mothers had experienced HPV themselves, they were more inclined to have their daughters vaccinated. Mothers were also more likely to have their daughters vaccinated if they felt comfortable within the medical realm – had had good experiences with physicians and exhibited a certain level of trust in the "system." In contrast, no mother who was suspicious of the medical sphere and business interests, such as "big pharma," allowed her daughter to be vaccinated. For these mothers, the risks of being vaccinated far outweighed any potentiality of disease. Across the board, though, mothers were quite annoyed at the gendering of the vaccine. As many mothers had both girls and boys, they wanted to provide what they deemed to be the best health care strategies to all of their children.

A] A School-based Vaccination Campaign, HPV Infection Risk Making and Mother Making

The first interview with a fellow mother regarding the vaccine took place in September 2009. This meeting with Carmen, who was 42 years old at the time, is still vivid in my memory. This poised and self-assured community college professor was clearly a bit rattled even though she was impeccably dressed in a linen ensemble with a beautiful statement necklace made of polished wood cubes; an outfit befitting the warm autumn days in southern Ontario. Carmen's daughter, Emily, had entered grade eight. This is a transitional time for young adolescents, the last year of middle school before high school. In the large packet of forms to be signed that Emily brought home on the first day of school, ranging from pizza ordering to school accident insurance requests, was an HPV vaccine consent form. Carmen brought a copy of the form to the interview. The most striking feature of the form was the large letterhead of the regional public health authority, highlighting the same logo that could be found on building signs, public notices in the newspaper and on posters placed in community spaces. The two-page form contained a letter to parents, an HPV fact sheet and the boxes to be checked for the required dual consent – that of daughter and parent or guardian. The consent form needed to be returned within four days in order for Emily to be eligible for the three-phased shot. As Carmen stated, “We got it on a Tuesday and it had to be in by the Friday.” The teachers explained the short turn-around as an administrative matter – time was needed to process all the paperwork for the three-part vaccination. Carmen, however, felt the process was rushed; she elaborated:

> I spent about three hours on the Wednesday night going back and forth saying should we have this done. It’s so new. Looking up the side effects, looking up if there were any long-term studies done on it. It seems pretty safe, but everything seems pretty safe when they’re trying to make everybody have it done.

At this point in our interview Carmen paused, and the stress of the decision-making process was visible on her face. This was a look that I would become familiar with during my interviews.

Andrea, an energetic entrepreneur whom I interviewed some months later in the winter of 2010 in her sun-filled office had a daughter in grade nine when we spoke. Andrea also commented on the narrow window for decision making:

> We didn’t have a lot of time, I remember. We had the information and we had to make a decision. I think we knew it was coming but the actual information that came from public health didn’t give us a huge amount of time. So I would imagine there were people who delayed that decision because they wanted to do their own research and they wanted to figure it out. I know in some cases people did go and have the vaccine later on that year and paid for it because they just needed more time and they didn’t want to have to do it in that environment [the school].

After the interview with Carmen, I looked more closely at the public health documentation she had brought to the interview. The letter from the public health authority was short, as was the fact sheet. The half-page letter began by stating that the Ontario government was providing the vaccination free of charge. The official logo of the public health authority and the endorsement of the vaccine by the provincial government, juxtaposed at the top of the letter, set an authoritative tone for this correspondence. The next paragraph – a mere three and a half lines – provided information on HPV. The description stated, "in 2006, there were an estimated 500 cases of cervical cancer with 10 deaths in Ontario".[34] The paragraph was brought to a close by saying that Gardasil® – the Merck Frosst vaccine purchased by the Government in Ontario – "can prevent the HPV infections that cause the majority of cervical cancer and genital warts in Canada." The remaining information in the letter focused on logistical aspects of getting the three-dose vaccine and the in-school vaccination procedures. The accompanying fact sheet offered half a dozen pieces of information (listed with bullet points) on HPV and the Gardasil® vaccine. The fact sheet emphasized that there were on average 400 deaths a year in Canada due to cervical cancer.

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[34] Please note that this document is not cited, as to do so would reveal the residential location of many interviewees.

Figure 4 - Typical Elementary/Middle School Sign in September

Data surrounding HPV and cervical cancer, however, is more complex than was presented in this public health literature. One might conclude that the information provided by Carmen’s local public health authority was not balanced and wonder what purpose the cervical cancer statistics served.

The stress Carmen experienced in making a decision regarding the HPV vaccine for her daughter came into relief in the days after she received the HPV vaccination consent form. Answers were not provided for questions such as: Is it safe? Does it really work?

And, if so, for how long? The mothers interviewed attempted to answer their questions by engaging in active information gathering concerning the vaccine, or put another way, they pieced together public health literacies.[35] Carmen discussed how she sought more details regarding the vaccine online:

> When we got the letter, the first thing that I did was go to the Web site that was on the letter, the public health authority web site. It was kind of vague and it was sort of "yes" this is great, you should have it done, no problems, blah, blah, blah. So I started Googling. That's a good thing and a bad thing, because of course the first thing that pops up on any Google search is Wikipedia, which can be written and re-written by whoever wants to add information. But as I started to go through a lot of other web sites, it put my mind at ease a little bit knowing that there hasn't been any long-term effects so far and that there – it was a very, very small chance of allergic reactions to it as well. So that was one thing that I was a bit concerned about because – she's – my daughter's – very healthy. She doesn't even take Tylenol®, so I don't know how she would react to a lot of medications. I think she's been on penicillin twice in her life and nothing else. So I was sort of hesitant about putting drugs in her that can't leave.

Carmen did not gather information solely through an on-line search, though. Since the introduction of the vaccination program in Ontario public schools in 2007, there has been a steady stream of newspaper and TV news stories. The vaccine has been covered in national and regional dailies such as the *Globe and Mail*, the *Toronto Star* and the news magazine *Maclean's* (Gordon 2009; Gulli et al. 2007; Picard 2007). While it was not surprising to see intense news coverage at the onset of the subsidized school-based

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[35] As per Pleasant and Kuruvilla, there are two types of health literacies: clinical and public health. In this chapter, public health literacies are meant to signify "the possession of knowledge about health . . . . [It] is thus a skill-based process individuals can use to identify and transform information into knowledge" (2008:154).

program, mass media coverage has been ongoing and particularly noticeable each September as the new school year begins. Carmen elaborated on this:

> At first I thought it was just something to scare to people again. When the flu shot became really popular everybody was like, "Oh you have to have a flu shot, have to have a flu shot." Everybody was saying you have to have a flu shot. Now it's not really that big a deal anymore.
>
> So I'm finding it's the same thing with this vaccine or this shot. You get a lot of – you have a ton of media coverage about it. They're playing on some of the worst fears that you can get. Either you getting sick and leaving your children or your children getting sick, which are your daughters getting sick.

In our discussion, Carmen continued by exploring the different angles mass media stories present regarding the vaccine:

> When you are reading about it in [an established] newspaper they come at it from a very scientific point of view. They seem to load you up on certain statistics but leave out other ones and those other statistics are picked up by these more popular media articles and they really play on your emotions. So you have the analytical versus the emotional with each of them.
>
> So, they elicit a very different response, When I read a newspaper article about it, I say to myself, "well that makes sense, that makes sense." But, when you see a heartbreaking story where a mother is holding on to her daughter and trying to protect her, you say to yourself, "Of course, I have to do it."

Like the mass media coverage of the vaccine, Merck Frosst's Gardasil® advertisement campaign was ubiquitous. I encountered Gardasil® advertisements throughout my fieldwork on television, in magazines, in pamphlets on the table in my physician's waiting room and even on banners strung up in the student centre at the university. My children even started to point out the advertisements before I spotted them. I was particularly surprised, though, when one Saturday morning my children yelled for me to come and see the Gardasil® advertisement that was playing during the commercial break of one of their favorite cartoons. Having had similar experiences, Carmen talked at length about the messaging of both the Gardasil® television commercials and print advertisements. Carmen recounted what she saw:

> The way they are portraying HPV and cervical cancer, it can happen to you. The people they are using in their ads are everyday looking people. So it sort of hits home a little bit. So it makes it all very real. The statistics that they throw up about how many women will have – will get HPV. Also, how many adults have HPV now and don't even know it. Do you know what I mean? It's sort of terrifying. Then you think is that me – did they miss something? [when she had her last Pap smear.]

Carmen felt advertisement messaging was "all about protecting your family and protecting your daughter and sort of instilling that sort of fear in you that it's around every corner." Carmen recommended I look at a particular print advertisement that was featured in that month's *Chatelaine* magazine, a periodical aimed at women that covers "family" issues and includes such things as recipes, housekeeping tips, fitness regimes, health information and fashion. Carmen described the advertisement she encountered, "Yeah. So it's in the family section. It's a mother and a daughter. The mother's got her arms around her daughter." For Carmen the messaging surrounding HPV vaccination promotion, whether through public health documentation, mass media articles or the Gardasil® campaigns[36] was that "good mothers" (O'Reilly 2004a:4, 2010) have their

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[36] The Gardasil® campaign has been a major source of information for mothers across the Province of Ontario as governments and public health authorities have not launched a public information campaign surrounding the virus and the vaccine. The lack of a non-commercialized information campaign is problematic from a public health perspective.

daughters vaccinated against HPV; good mothers are responsible for mitigating HPV risk for their daughters by getting their daughters inoculated.

My daughter means the world to me.
Which is why I do everything I can to help protect her.

I just learned about HPV (Human Papillomavirus), a common virus that about 75% of sexually active Canadians will have at least once in their lifetime. There are many different types of HPV. Some are harmless and most clear up on their own. Some can affect the genital area and may cause cervical cancer, genital warts and other diseases.

HPV infection is most common in teenagers and young adults. That is why I am doing everything I can now to help protect my daughter against 4 types of HPV.

Getting my daughter vaccinated with GARDASIL® is one of the ways I look out for her. After all, what are moms for?

What would I do to help protect my daughter from HPV, cervical cancer and genital warts?

Everything I can

Learn everything you can.
Do everything you can.
Talk to your healthcare professional.

GARDASIL® is the only vaccine that can help protect your daughter from HPV, cervical cancer and genital warts. Talk to your healthcare professional about getting her vaccinated now.

Indicated in girls and women 9-26 years of age, for the prevention of infection caused by HPV types 6,11,16, and 18 and the following diseases associated with these types: cervical cancer, abnormal/precancerous cervical cells, vaginal/vulvar cancers, abnormal/precancerous vaginal/vulvar cells, and genital warts. GARDASIL® helps prevent these diseases but it will not treat them. GARDASIL® does not protect against all types of HPV and, as with all vaccines, it may not fully protect everyone who gets the vaccine. GARDASIL® has been shown to be generally well tolerated in children and adults. The most commonly reported side effects in girls and women were pain, swelling, itching, bruising and redness at the injection site. Fever, nausea, dizziness, headache and vomiting have been reported. Duration of protection over the long term has not yet been established. Regular Pap testing should continue even after vaccination with GARDASIL®. Vaccination with GARDASIL® is not recommended during pregnancy. Talk to your healthcare professional to determine if GARDASIL® is right for your daughter.
HPV = human papillomavirus

GARDASIL®
[Quadrivalent Human Papillomavirus
(Types 6,11,16,18) Recombinant Vaccine]

®Registered Trademark of Merck & Co., Inc. Used under license. HPV-09-CDN-84140625-JA

For more information, go to
www.gardasil.ca

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Discovering today
for a better tomorrow.
Merck Frosst Canada Ltd., Kirkland, Quebec

Complete information about GARDASIL® is provided in the GARDASIL® Product Monograph, Part III Consumer Information available at www.gardasil.ca

Figure 5 – *Chatelaine*, October 2009

B] On-the-Ground Stress: Negotiating the HPV Vaccine for Daughters

The mothers I interviewed were clearly stressed about the HPV vaccine due to the short period of time they had to make a decision. Additionally, being bombarded with mass media messaging that, ultimately, tied their decision to the type of mother they were compounded their stress. Once this stress had been brought up in our interviews, they moved swiftly to their actual HPV vaccine decision-making processes and rationales. Pragmatically, HPV vaccine negotiation strategies tended to fall into two groupings: (1) mothers who opted to have their daughters vaccinated (12 mothers or 60 percent of mothers interviewed); and (2) mothers who did not wish to have their daughters vaccinated (six mothers or 30 percent of mothers interviewed). These numbers are presented in graph form in Appendix M. The mothers who vaccinated either had their daughters inoculated through the school system or by their physician because the daughter was older than 13. When a physician vaccinated a daughter this was done at the mother's expense or paid through an insurance plan. Mothers who did not vaccinate chose to opt out of the school-based program because of their concerns regarding "big pharma" and the gendering of the vaccine. Two mothers (ten percent of mothers interviewed) decided to delay the decision to have their daughter vaccinated. I do not focus on these narratives in this chapter because in these two cases, the mothers could afford to have their daughters vaccinated at a later date through their private insurance plans. They did not have to rely on state-sponsored vaccination to have their daughters vaccinated and this clearly contributed to their decision to wait – they could afford to put off a decision until further research on the vaccine would be released. They were in the privileged position of being able to delay the vaccination and thus ease their minds regarding what was widely perceived as a new vaccine. However, to place undue emphasis on decision-making outcomes would provide a shallow reading of the data.

Decision making is complex and non-linear. It reflects not only a mother's personal health-related experiences, but also her mothering strategies.

1. Opting to Vaccinate: Saying "Yes" to Mitigate Cervical Cancer Risk and Sexual Health Negotiation Challenges

Andrea recounted a decision-making process that reflects narratives common to the mothers interviewed who opted to have their daughters vaccinated. Andrea worried that her daughter, when eventually a mother herself, would not take the precautionary steps to ensure that she did not develop cervical cancer. Andrea explained that mothers often "tend to focus on the health of their families, so there may always be a time issue for women to be able to go out and get a Pap test. Women probably put it off, focusing on their children's health instead." Therefore, as a way to relay the importance of a woman's health, particularly that of a mother, Andrea incorporated her daughter's opinions and views into her decision-making process. Andrea explained, "She certainly had input into the conversation. It wasn't my decision that said, 'I'm making this [decision] for you.' We certainly had conversations around what this meant. It was something where – and, this is where technology is great – you can go and look at information like this on the Internet." Besides talking to her daughter, Andrea consulted friends, conducted research on the Internet and spoke extensively with her family physician. Andrea detailed this process:

> I did talk to our paediatrician to get his thoughts. He is a highly experienced doctor and he has three daughters as well. He said that if he was in the situation where he had to make this decision for them that he would 100 percent go ahead and do this. So I think that it was a hard situation to be in as a parent, having to make that decision, because it wasn't my body that I was making the decision about, but it was more of a preventative discussion.
>
> I also did talk to other parents, not that I was going to let other people's opinions about what they would do for their child sway what I would do for mine, but certainly just to get a range of comments and discussions.

Carmen also incorporated her daughter into the decision-making process:

> I wanted her opinion on it too. I didn't want to say okay, by the way, in three days you are going to get stuck with a needle. I didn't want her to have to be surprised by it. So we had a long talk about it. She understands that in the long run it could help her. Sure it sucks that you have to get three needles.

Central to Andrea's decision to have her daughter vaccinated was the mitigating of risk for her daughter. Andrea was acutely concerned about "what will happen in five years time? What are the implications of doing something like this?" Andrea elaborated on her assessment of the risk of the HPV vaccine:

> It's very similar to things like meningitis vaccinations or chickenpox vaccinations, all of which my children have had because again, I felt comfortable looking at the risk around vaccination versus the risk of getting the disease or having an illness that could have been prevented or, at least, the impact reduced. So, we spent a lot of time talking about this because, it was just again – I think that with decisions like that if they affect me only are easier, whereas as the parent you take on that responsibility of "what if?"

Carmen also talked about the HPV vaccine's potential risks; these risks were ever-present for her:

> There's certain risks associated with everything. So, absolutely I'll be very careful watching her [after she gets the HPV vaccine]. After she got her hepatitis B shots last year, I spent the next couple of days analyzing. She had a bit of a sniffle. She had a bit of a bruise for it, so I was watching to make sure that nothing spread.
>
> So, it just puts you on guard. But because it seems so new, I don't know. Even the long-term studies I was looking at weren't very long-term. Do you know what I mean?

After talking about potential risks of the HPV vaccine, Carmen zeroed in on her rationale for deciding to have her daughter vaccinated:

> As a mother the last thing I want to do is have anything bad happen to her. This was sort of like a 'catch-22' because if I do not let her have it and then if she ends up getting cervical cancer I'll always blame myself because I had that chance to get her the shot. So that weighed heavily on my mind.

Heather, a physiotherapist and a mother of four with one daughter in grade eight, also clearly expressed the potential risk of vaccines. As we ate lunch on a rainy and dark mid-November afternoon in her dining room, Heather explained:

> I think there is always risk with a vaccine. I think some people will react badly and I think always there is a risk that we are going to find out some day later, like with any kind of medication or anything like that, there are some long-term effects we didn't realize. I think that there is always a risk.

For Carmen, Andrea and Heather, the vaccination involved risk, but there was the greater risk of not having their daughters vaccinated. None of the mothers wanted their daughter to contract an HPV infection that could eventually lead to cancer, particularly if they could have had her vaccinated against it. However, Heather's rational for vaccination went beyond a "what if" scenario and was layered with her own health history. Heather, who had HPV-related complications in her early 20s also made her vaccination decision based on her HPV-related treatment experiences.[37] Heather detailed contracting an HPV infection, which turned into dysplasia two decades ago:

> Actually after university one of my Pap smears came back as irregular and I had to go in and have a biopsy done and I was at – how many stages are there in cancer? I was at the second, I was not at the final one, but the one before that and had to go in and have, I'm kind of embarrassed because I don't really remember a whole lot about it. I had to have a procedure.
>
> So it took a day. You went in in the morning and then I think I went back home that night. I had a friend come and stay with me for a few days after that. They told me it was HPV. I have met so many people who've had it, a friend of mine who came to visit from out-of-town recently was going through it at the same time and she just started crying one day and I asked, "What's wrong?" And she said just wait a minute and stop [they were driving at the time.] I had exactly the same thing. I said to her, "Remember after university? I had it".
>
> They [the doctors] told me I had cancer. When they told me, I was on my own. I'd split up with my boyfriend, I was living by myself and I was like, "Oh my God, I'm going to die." I remember thinking, "Do I have to tell people?" "What do you do about that?" [Meaning did she have to tell past sexual partners.]
>
> I am surprised at how many people you find out about later. Of course, you don't just bring it up [laughs]. It usually comes out if something happens later.

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[37] Heather was the only mother who outlined HPV-related treatment experiences when it is very likely, given the prevalence of HPV infection, that other mothers had also undergone similar procedures. I am not certain why other mothers did not talk about contracting HPV infections and can only hypothesize that they were not comfortable talking about sexual relations in general, as was evidenced by their unwillingness to talk about sex with their daughters.

Heather wished to spare her daughter the same experience, particularly the vulnerability she felt when diagnosed with an HPV infection. Heather elaborated on challenges inherent in sexual health negotiation:

> I mean, I don't ever want her to go through that, and if it's a way to prevent it then, you know. And I think if somebody – because you can never trust 100 percent whoever you are with because they have trusted somebody – you can never know 100 percent ever, right. You might even wait until you are married and then, lo and behold, they didn't know and she gets it. She's going to get the shot, everybody should have it.[38]

Both Andrea and Heather spoke of making a decision on their own. While they did consult peers, physicians and on-line health information and talked to their daughters about the impending vaccination, the main responsibility for the vaccination decision fell on their shoulders, even though they both had husbands who were active fathers. Andrea expanded on how the responsibility for the decision fell to her:

> I mean certainly my husband was consulted as well, but I guess that I sort of saw it more as a female decision just because I had experienced some of these things that no one else in the house had in terms of having had Pap tests and understanding some of the preventative things that women do that men don't necessarily have to do. So I think it was primarily me that took the lead on looking at the issues and talking to other people. I think mothers tend to do this – we are the ones that take on the role of health management in the house. As a mother, I was aware that this is another role that you take on making decisions for other people.
>
> I think by experiences with my friends is that it was seen as more of a women's issue than one that really involved men [Andrea is referring to her friends'

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[38] Heather was also the only mother who touched upon vulnerability and sexual health negotiation. This theme is explored in more detail in Chapters Five and Six about students and patients.

> decision-making experiences]. So it was not a decision I made in isolation, but it was one where certainly I played more of a role than my husband did and my daughter also had a decision-making role because it was her body and she was the one that was going to experience it.

Heather was even more direct when discussing her role as decision maker in the household and her spouse's role in the process: "If he didn't agree with it, that would just be too bad. I mean he does agree too because he knows everything that has gone on [with me] and you know, so he is in agreement, but if he wasn't in agreement, she would be getting it anyway. [She laughs]. I would overrule that."

Carmen's husband actively participated in her information search:

> At first he said it was up to me. Whatever I decided would be fine. But the more he saw that I was stressing about it, the more he stepped up to talk me through it. He didn't make the decision – he didn't help me make the decision necessarily, but he was asking me leading questions.
>
> He was asking me questions that made me go, "Oh, yeah, I didn't think about that or "Oh well that makes sense, so I'll look at this." So, it was more helping me along rather than saying, "To do it, you have to do it."

The ultimate decision making did fall to Carmen, but she received spousal support throughout the decision-making process, which she felt helped ease some of her stress. The support Carmen received from her husband in her research, though, was certainly the exception amongst the mothers interviewed.

2. Not Vaccinating: Saying “No” to Perceived Health Risks and “Big Pharma”

Colleen, a neighbor with a home-based business and a daughter approaching grade eight, emphasized that grade eight girls were being treated like, “a case study. It seems like, let’s track these girls and see what happens.” During our interview Colleen spoke about how it was her duty to protect her daughter from the dubious interests of “big pharma.” Colleen was by far the most animated of the mothers I interviewed.

Colleen was so energized by this topic that when I first arrived at her home and before I took off my coat, she began what was to be the first of many lengthy monologues concerning the vaccine. Colleen started the interview by explaining:

> I looked into it and what, we have three to four hundred deaths a year from cervical cancer. We have a death every seven minutes from heart- and stroke-related disease. And we're spending $300 million and 300 people a year on average are dying from cervical cancer. Cervical cancer is quite preventable with regular Pap screening. So, what the heck. And this vaccine is only protecting, they say, 70 percent of the cases. But there are all these other strains of HPV it’s not protecting against.
>
> So why are we spending hundreds of millions of dollars to vaccinate against a disease, or at least 70 percent likelihood of getting this, when this is one of the few types of cancers that is preventable with screening and they're saying well, guess what? You still have to practice safe sex, which people should be anyways, and you still have to screen. And there’s no guarantee that you’re still not going to get it.
>
> So there’s a huge disconnect. So who wins with the vaccinating? Who’s winning? Well, you know who’s winning—the company that’s getting paid hundreds of millions of dollars and that’s just from Canada. The same company is also manufacturing the vaccine for the States, virtually everyone else. So how much money are these guys making?

Colleen was referring to Merck Frosst, as the "winner," and she questioned the necessity and effectiveness of the vaccine. Colleen was not, however, anti-vaccine[39] per se as she did have her daughter vaccinated with the routine infant schedule. However, Colleen tiered vaccines; she split vaccines into those she deemed mandatory and those that were not. Our interview was conducted in the early winter of 2010, just after the H1N1 vaccination offering in the fall of 2009, and she was quick to point out that she did not immunize herself or family members against H1N1. Colleen explained:

> Here's the thing with H1N1 – it's not as necessary. Flu vaccine? It's the flu. The flu mutates constantly. They have no idea what's coming at us. But they spent all this money, they were getting people, they were scaring people into injecting themselves and they put adjuvants in the vaccine. And, we don't even know what we are injecting into ourselves half the time.

For Colleen, vaccines that she deemed non-mandatory presented an unnecessary risk to one's health and in the case of the HPV vaccine, this risk would be brought upon her daughter. Colleen's conceptualization of health risk changed after having a child:

> I think that since my daughter has been born, I've gotten much more interested, I've got more invested in my own health. So I'm a little more aware now of

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[39] The common perception in popularized and medical discourses of being "pro-vaccine" or "anti-vaccine" (Blume 2006; Jacobson et al. 2007; Poland and Jacobson 2001; Poland et al. 2009; Streefland et al. 1999) is a simplistic binary that does not represent the mothers, students or patients interviewed. Not one mother mentioned that they decided not to have their children vaccinated with the routine measles, mumps and rubella (MMR) protocol, which is sometimes linked in popularized discourses to autism (McCarthy 2007). As such, there is a small body of academic literature focusing upon parental attitudes towards autism and MMR vaccines (see Petts and Niemeyer 2004; Poltorak et al. 2005; Skea et al. 2008).

> what goes into your body is going to affect how you feel. So I try to eat healthy and I try to avoid things that are going to have a negative impact on my health.
>
> But it's like saying well, if you walk down a dark alley at 2 a.m., you're going to get mugged. Well, no, you're not necessarily. But if you don't have to walk down that dark alley at 2 a.m. and you can avoid that risk, take another path, you know, don't walk down there. So that's kind of my attitude towards mitigating risk, is that I'm not going to smoke, 'cause I'm not an idiot. I know that. But I did when I was younger. You think when you're younger that nothing bad can ever happen to you, right? You can drive down the road smoking a cigarette and eating a Big Mac, going 125 on the highway—not that I ever did that.
>
> You never know what is going to happen to you. And I could get in the car – I'm totally jinxing myself – to go to the doctor's and I might get hit by a truck. I don't mean I'm not going to drive. So, you have to maintain a certain amount of – you don't want to be complacent, but you can only do so much, right? You can only do so much.

Colleen's comments illustrate how she was more vigilant about health risks as she got older and became a mother. However, her rendition of risk and public health literacy was different than Carmen's, Andrea's and Heather's. For Colleen, health risk was about taking in contaminants, like tobacco, or "unnecessary" vaccines. She also believed that as a society we have become more aware of potential risks to the point of paralysis. In response to, and in resistance to, living in what she perceived as a "risk society" (Beck and Willms 2004), Colleen chose not to over think every potential risk. Thus, for Colleen, pharmaceuticals, which are manufactured by for-profit companies, bring about greater risk than the HPV virus itself, and she was actively resisting Gardasil® advertising that, in her own words, was set to make all mothers "afraid" for their daughters. Therefore, in this line of thinking, Colleen was being a good mother by protecting her daughter from the HPV vaccine, both in terms of potential vaccine side effects and "doing too much" to avoid perceived and hyped up risk. Both the vaccine and too much stress were deemed to be "unnatural" and, thus, unhealthy. In keeping with wanting to live a "natural" life, Colleen mentioned she only served organic fruits and vegetables to her family and abstained from eating goods baked with white flour or white pasta or rice.

In terms of vaccine decision making, Colleen, who was married, made all of the health-related decisions in the family for her daughter:

> I make them. I make the decisions, for my daughter and I. For example, the H1N1 [vaccine], I didn't say to my husband, "Do you think we should vaccinate?" I said to him, "I'm not being vaccinated, our daughter's not being vaccinated." And he said, "Well, I probably will." But he never did.
>
> I mean if it's a bigger decision, when it involves selling your house and moving town, I can't make those decisions myself. But my husband would not question any decision I made about our daughter's health. Anything to do with this sort of thing, to vaccinate or not to vaccinate, it would be solely my decision – the day-to-day stuff. This to me would not be big picture. I mean, maybe to someone else it's a big-picture decision. To me, like H1N1, there's no way my daughter is being vaccinated. Her whole class could have been dropping like flies; she still wasn't getting that vaccine in her arm. If they would have said she can't come to school without the vaccine, I would have said, "Fine, you know what? Give me some homework for her and I'll keep her home until this whole thing blows over."

The passion Colleen exhibited about this topic was typical of all of the mothers I interviewed who decided not to have their daughters vaccinated. Theirs was a passion with no room for change and all decisions appeared to be fixed. They were not likely to change their minds as their daughters aged, even if they could have afforded to pay for their daughters to be vaccinated outside of the subsidized school setting.

C] The HPV Vaccine and Adolescent Sexuality

While mothers were happy to talk about the vaccine at length, they were more reserved when it came to talking about adolescent sexuality. Even when a daughter was past the grade-eight vaccination age, mothers treated the prospect of sex as a theoretical construct, rather than a possibility, if they discussed sexual relations at all. While mothers were reluctant to address teenage sexuality, only one mother, Margot, discussed abstinence, although she did not specifically use this term. The mothers had been teenagers in the 1980s and young adults in the early 1990s and therefore were not generally of the generation to be actively influenced by abstinence discourse. While abstinence discourses have existed for centuries, the folding of these discourses into American public policy was at its height in the early 2000s with President George W. Bush's active promotion of abstinence in American domestic and foreign policy (Gresl-Favier 2006).

Instead of focusing on sexuality, Colleen talked about how middle school girls physically mature at different stages (much faster than her own daughter had), but that psychologically they were still "girls" as opposed to young women:

> You see that there are kids in their class – these girls that were mature two years ago. And the way they were in grade 7 is as mature as they are going to be. You know, they have their adult body, they are as tall as they are going to get, they are busty, they are fully developed. But they are still little girls in grade 7 and I don't think that has changed a lot.

Most mothers still viewed their daughters as "girls" even though they were fast approaching, or were even in full-blown puberty. Carmen, however, was a little more practical in this regard and broke the pattern of not wanting to discuss sexual relations with a daughter:

> I talked to my daughter about it. That was something that was a little bit difficult because I knew that I would have to bring up sexuality. We are very open about that in that I have talked to her from a very young age about her body, what is happening to her body, as she's getting older. We've discussed preliminary things about sex and she still thinks it's gross. So I'm okay with that.
>
> Having to discuss something like this with her, I can see where somebody who doesn't have that sort of the relationship with their child, where they would be – where it would be awkward or where it would difficult to do it, because we have – I guess because I had her when I was younger and so we're – I guess we're closer in age than a lot of mother and daughters are.
>
> We have – we still have a little bit of a friendship on top of being parent and child. So she was asking some pretty frank questions, like why do only girls have to get it. Then someone – a girl in her class said that only sluts have to get it. So I don't know if that's coming from her family or if it's talk that she's hearing. So I had to explain to her that's absolutely not true. I said – and that's just – so discussing it with her was the one way that she would be okay getting it and then that's when I started to do all of the extra stuff after she went to bed, and talked with my husband about it after she went to bed.

Even though Carmen was more open about talking about sex with her daughter than the other mothers, she still had some difficulty having these discussions. This is interesting because the university students who were interviewed (and are featured in the next chapter), were quite vocal in wishing that society as a whole and their parents had been more open about talking about sex with them.

Sexuality and religion did not enter into my interviews with mothers, except for one lively interview with a devout, evangelical Christian named Margot. Even observant Catholic mothers, such as Carmen, talked about how the Catholic schools they sent their daughters to held information sessions for parents that promoted the vaccine.[40] The school Carmen's daughter Emily attended holds a meeting for parents every fall geared at parents with daughters in grade seven so that they have an entire year to think through their vaccination decisions. An active member of the school's parent council, Carmen explained the reasoning behind the meeting:

> I know there were more strict Catholic parents who were really worried that it would have to lead to discussions about sexuality with their daughters at an age that, maybe, their daughters weren't ready for. Or, maybe, the parents weren't ready for.
>
> So, there was talk about how to approach this and how to approach it within the community. So our school said the Province is recommending that this be done, so we're going to do it. If there are any hard questions, we'll answer them within a Catholic framework and we'll go from there.

The overwhelming majority of mothers I interviewed – 75 percent – were observant in their own faith traditions (see Appendix M). As such, 15 of the 20 mothers described themselves as regularly taking part in religious activities. Of the 15 religiously oriented women, ten self-described as Catholic, two as United, two as Anglican and one as a born-again Christian. However, faith did not come to bear upon their decision making, save in Margot's case. Margot, a stay-at-home mother of five, would not vaccinate her daughters as she felt vaccination would send the wrong message regarding pre-marital

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[40] As of 2012, of the 29 English-language Catholic school boards in Ontario, only two did not permit HPV vaccination in their member schools (Wilson et al. 2012:34-36).

sex. Margot worked hard to shape her household around “Christian values,” as she put it. When talking about STIs, Margot felt strongly that they were linked to promiscuity and that there was an appropriate biblical quotation to explain what she meant. Margot quoted Galatians 6:8, “The one who sows to please his sinful nature, from that nature will reap destruction.” But Margot did not offer the second half of the verse which reads: “The one who sows to please the Spirit, from the Spirit will reap eternal life.” Margot felt that pre-marital and extra-marital sex would lead to dubious health outcomes, including STIs. At the end of her interview Margot mentioned that she had stayed up late the night before in order to gather her thoughts for our chat. Margot took the interview seriously and was anxious about how her born-again Christianity would be portrayed in my research. This brief mention of Margot has been included to note that religion only ventured into one mother’s decision-making process. Religious objections to the vaccine and related views of sexual morality had been mentioned in casual conversations with other academics prior to my fieldwork research, yet in the end only one mother raised it as an issue.[41] The Christian right in Canada has been largely silent regarding the vaccine during its roll out and this is, perhaps, as Epstein and Huff suggest, due to the overall de-sexualisation of HPV in the pharmaceutical promotion of the vaccine (2010).

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[41] This was not surprising as during George W. Bush’s tenure in the United States, conservative groups did not tend to object to the vaccine. Only when states advocated for mandatory vaccination did conservative groups voice objections to the vaccine. This objection was due to the compulsory nature of administering the vaccine and not the vaccine itself (Epstein and Huff 2010:221).

Conclusion

The mothers who were interviewed for this study were greatly stressed by the decision making that they faced surrounding the HPV vaccine. As Carmen stated, “it weighs heavily on my mind.” All mothers, whether or not they decided to vaccinate, were, in essence, being good mothers. They researched the vaccine extensively, talked with physicians, friends and their daughters in order to come to a decision they felt comfortable with. In the end, decision making rested within the realm of personal experience – it was not a linear, risk/benefit equation. If a mother, like Heather, had experienced HPV herself, she was likely to have her daughter vaccinated. If a mother was comfortable within the medical realm, she would often view the risks of vaccination as she would another shot, such as the chickenpox vaccine or other routine childhood scheduled vaccinations. However, this does not mean that mothers who opted to have their daughters vaccinated were firm that their decision was without any sort of risk. Their uncertainty was agonizing for them. For example, Carmen felt she was potentially bringing risk to her daughter Emily because there was no body of research concerning the long-term risks of the vaccine. However, if she did not get Emily vaccinated and she did eventually get cervical cancer, she would never forgive herself. Few mothers who decided to vaccinate had the level of certainty that Colleen possessed. Mothers like Colleen who distrusted the medical sphere and big business interests, such as “big pharma,” were never going to get their daughters vaccinated. For them the risks of taking a vaccine far outweighed any potentiality of disease. Interestingly, Colleen called me in the fall of 2012, about two-and-half years after our initial interview. She was livid that her daughter's high school sent home a letter from the local public health authority strongly urging her daughter to be vaccinated as they had declined inoculation in grade eight. Colleen felt this was an abuse of authority and would, as she said, "like the state to stay out of her mothering decisions." All of the mothers interviewed also wanted the government to stop gendering the vaccine. Ultimately, mothers enacted what they deemed the best health care strategies for their daughters, but the pressure – whether it was from pharmaceutical advertisements or public health notices delivered via their the local high school – did not sit well with them.

CHAPTER FIVE - "Let's Talk About Sex": Women University Students Share Their HPV and HPV Vaccine Stories

"Let's Talk About Sex"

Punch it, Hurb
Yo, I don't think we should talk about this
Come on, why not?
People might misunderstand what we're tryin' to say, you know?
No, but that's a part of life

Come on

[CHORUS]

Let's talk about sex, baby
Let's talk about you and me
Let's talk about all the good things
And the bad things that may be
Let's talk about sex
Let's talk about sex
Let's talk about sex
Let's talk about sex

Let's talk about sex for now to the people at home or in the crowd
It keeps coming up anyhow
Don't decoy, avoid, or make void the topic
Cuz that ain't gonna stop it
Now we talk about sex on the radio and video shows
Many will know anything goes
Let's tell it how it is, and how it could be
How it was, and of course, how it should be
Those who think it's dirty have a choice
Pick up the needle, press pause, or turn the radio off
Will that stop us, Pep? I doubt it

All right then, come on, Spin

[CHORUS]

Salt’N’Pepa, Let’s Talk About Sex © 1991(First Half of Lyrics Only)

Introduction

While Salt’n’Pepa’s successful song was released when North America was grappling with the spread of HIV/AIDS and when there was a steady stream of media coverage (Patton 1990) which inhabited a large chunk of the mediascape (Appadurai 1990), this song kept popping into my head while writing this chapter in the summer of 2012. Of course, the students interviewed for this chapter were mere toddlers or quite young when this song was released, but they are essentially “singing its refrain.” Move ahead two decades – with a different STI-related illness, this time HPV instead of HIV – and the same cultural orthodoxy of avoiding “talking about sex” persists.

As a result, this chapter is about university students’ HPV stories, as Sylvana so eloquently put it. It is about their urging for widespread sexual health education concerning STIs, and specifically HPV, and their deliberations surrounding the HPV vaccine. Interviews were intense and emotion-filled events in which students off loaded their anxieties about having contracted an STI, most generally genital warts, while receiving very little social support. Many felt too stigmatized to share their experiences with friends, family and peers. These experiences led students to strongly urge for in-school and societal sexual health education programming, which could help to de-stigmatize STIs and to bring an element of balance into sexual health negotiation. Young women are too often tasked with the responsibility for ensuring “safe” sexual health negotiation within sexual encounters and bear the brunt of the blame when an STI is contracted. Women are being positioned as bearers of sexual disease (as is demonstrated and reinforced in HPV vaccine advertising and the girls-only school vaccination program) and they feel vulnerable within this realm of negotiation on an individual level. The gendering of HPV and the HPV vaccine, both through Merck Frosst marketing and within the governmental realm of school-based vaccination programming in Ontario, was off-putting to students. This concern regarding gendering and uncertainty vis-à-vis potential long-term side effects meant that the majority of students interviewed decided not to get vaccinated or to delay vaccination. Their saying “no” to the vaccine was their way of saying “no” to HPV gendering and potential vaccine risks.

However, before delving into the stories of university students, it is important to briefly describe how this extra cohort became a part of the research project. Sometimes being “in the right place at the right time,” as they say, can result in the field coming to you. Throughout much of my graduate education I worked as a teaching assistant and did so throughout fieldwork as well. During my first tutorial in September 2009, students began the session in their usual manner – tired and not quite into back-to-school mode. However, when I mentioned my research they perked up. All of a sudden lively discussion ensued. The students talked about everything from their sex lives to having had HPV infections to how sexually transmitted infections are socially experienced differently for young men and women. They even openly debated whether or not to get the vaccine. I was the only one in the room who was shocked about how open the students were. At the close of this first class, Sylvana approached me as students were leaving. She wanted to talk to me about her HPV experiences. She was not the only female student who spoke with me after class to ask to be interviewed, to seek my advice on whether or not to get the vaccine or to share her experience of having contracted an HPV infection, but she was the most determined.

Figure 6 – Two HPV ads (Gardasil® on the left and Cervarix® on the right) in window outside pharmacy beside campus health clinic, 2010

As the course progressed, I began to realize that something was going on with the young women in my class. They really wanted and, more importantly, *needed* to talk about their experiences surrounding HPV infection and the HPV vaccine. The research project, with its focus on the HPV vaccine, provided an avenue through which young women could articulate their personal experiences with HPV infection and their concerns about whether or not to get the vaccine. Working while doing fieldwork brought unexpected changes to my research; the class I taught was a turning point in the research process. It was during this class that it became apparent how common HPV infections were[42] and that no one was talking about them publically. After waiting for university ethics approval to interview former students once the course had finished, Sylvana was the first student interviewee. This was in the winter of 2010.

A] HPV Stories: Genital Wart Experiences

On that cold afternoon, Sylvana entered my office, took off her large, puffy winter coat and sat on the chair set out for her. She had a large knapsack-cum-suitcase with her and she opened it up to reveal several file folders of HPV research and news clippings. Evidently, Sylvana had thoroughly prepared for our interview. This was not surprising, considering her parents were both physicians, she was a health sciences major and, as our interview revealed, she was a frequent medical consumer. After bringing out her research from her bag, Sylvana sat down, sighed loudly and asked how I was doing. After formal pleasantries were exchanged, Sylvana delved straight into her HPV story.

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[42] While HPV infection is common among students, the resulting complications are generally not long lasting for young women (which usually manifest in genital warts or an abnormal Pap test result). On the other hand, women a few decades older experienced multiple abnormal Pap test results over a protracted period of time, which would not clear without surgical intervention. These types of HPV infections, the resulting medical interventions and HPV vaccine decision making are discussed in the next chapter, which focuses on the hospital portion of my fieldwork.

Sylvana swiftly recounted her discovery that she was carrying an HPV strain, which manifested itself in genital warts:

> I was scheduled for a specialist appointment last summer and it was an infectious disease appointment and I wanted to go because I have a few enlarged lymph nodes and I didn't know what they are related to. I have had lymph nodes enlarged as a teenager and I know that they have gone down to their normal, whatever, lymph pathway. They have gone back to a size that you can't even detect them in about two weeks or so. So I know that for my body that wasn't normal and I kept explaining that to my family doctor and she said, "Well there is really not much that I can do." I ended up seeing an infectious disease specialist for them. I have the practice of getting all of medical results together every time I see a specialist and just presenting them to the specialists just in case, you know, they can make sense of something that I can't tell them.
>
> So it so happens that that day I came from a family doctor with all of my results at home and among the results there was this piece of paper that said *Condyloma Acuminata* [genital warts] on it and I was like "Oh, I don't remember this one." So I read through it and it turns out it was the histopathalogical report from when I went to see the dermatologist in the spring for what they call a "skin tag." So both my family doctor and the dermatologist thought that it was just a vulvarous skin tag but it turned out it was *Condyloma Acuminata*, which is caused by HPV. So, I found out my result at home. I was shocked.

Not only was Sylvana startled to find out she had genital warts – without notice from a physician or the physician's office – she was surprised that a lapse in information sharing occurred in Canada, as she felt she had received excellent care here, as opposed to her experience in her natal country, Slovakia. Sylvana explained how she reacted to the unexpected news and her subsequent course of action:

> So then I called the dermatologist's office and I said, "can I schedule an appointment with the doctor?" and then when I saw the doctor I said, "how

> come nobody called me about this?" She said, "well I did write down for the secretary to call you and nobody called you?" I said "no." So it was just, I guess, down to the secretary level that something happened. *Condyloma Acuminata* is not, it is a big deal but it is not as big of a deal as finding out that you have cancer by yourself or something worse.

Sylvana was not alone in her HPV infection story, particularly that of having genital warts. Maya, a 27-year-old masters nursing student was researching sexual health education as her major research project, and had a similar story. She described her experiences contracting STIs, both herpes and genital warts:

> Yeah, I'm so lucky to be in the field that I am and that like, because I have definitely felt that isolation before, like I had herpes when I was 19. I got it when I was 19 and I was like, that virus is very complex as well and I think it's so weird because of its very, very serious association between depression and herpes.
>
> No one really has ever thought about that, right. They think, okay, it's an STI, you get it but there's so much, so many layers of psychosocial stigma attached to it. And it's very common for people with that. And I'm sure the same thing can be said for HPV. Personally I think it's much less severe, like HPV is pretty A-okay as far as STIs go.
>
> Yeah, in comparison, but there is like, it's not, we're not just looking at the physical sort of expression of these diseases well, depression is a physical ailment as well, but there's so much emotionally that goes on with women. And that's not being talked about and it's not being part of our treatment that we get when we have this. Like you go to a doctor's office and they like read a result and then you have to figure out what you're going to do with it and then that's really hard when it comes to HPV or when it comes to herpes or any of the STIs. We're not given the support that's really necessary in order to cope with this.

A culmination of personal experience and academic training led Maya to passionately advocate for a social reframing of STIs. Instead of being considered a big or traumatic event, she argued that, "people should think of HPV as part of a normal, healthy sexuality because it can't necessarily be prevented, so if you are going to have sex, you are going to end of up getting HPV, probably, at some point. And it will go away on its own for the most part. The stigma is so silly because everyone is going to have it at some point."

While Maya was very pragmatic about STIs, Sylvana was not as relaxed and needed some time to get over the initial shock of her discovery.[43] Additionally, Sylvana was worried about the long-term implications of having contracted genital warts. She talked about her fear regarding the impact having an HPV infection today may have on any future children she would have:

> What really had a tremendous impact at the time was when I found out that I had an HPV infection, that had a huge impact and my first thought was: how is that going to influence the fact that I want to become a mother one day? Because it's extremely rare but my understanding is that in some cases children can get laryngeal warts while in utero and there are other effects that a woman's infection can have on the child. So I was really scared that to me that would be extremely humiliating to have my, I guess I could call it, irresponsibility of not wearing a condom stamped on my child's body.

Sylvana did not just want to ruminate about the potential future effects of an HPV infection, she also needed to share her current experiences:

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[43] It is important to note that while Sylvana was the only student who found out about her diagnosis on her own while leafing through her medical records, it was fairly common for students with genital warts to be misdiagnosed, sent to the wrong specialist or have to visit several physicians before receiving an accurate diagnosis or even a diagnosis at all. Students reported that their GPs were stumped when presented with genital warts and a referral to a dermatologist was a common route followed when a GP was unsure of what to do.

> I am clear of it now, but my boyfriend is just on his last treatment. I've been researching non-stop. I mean, I've looked at it. Thank God mine aren't internal . . . mine weren't internal, so they are just on the outside of the surface of the skin and that . . . like they said, that's a low, low type of HPV [low-risk HPV strain].[44]
>
> So they were saying that's a low-risk type, so I was thanking God for that. I am not trying to be explicit, but for my boyfriend, he didn't have any on the head of his penis. I was thankful for that because it would have put me into more complications, more problems. I don't even know what the treatment would have been, because that area is so sensitive, like ours internally is so sensitive. It was just on the surface of the skin.

Sylvana explained that she and her boyfriend did not even realize they had genital warts until her discovery while leafing through her medical records. As we spoke in my office on that cold Toronto winter day, I was beginning to understand why Sylvana so urgently wanted to talk to me. She had been holding in a lot regarding her HPV infection. In addition to the fear that she was harboring regarding future children and her discomfort discussing the details of a genital wart infection and treatment with others, there was something else troubling Sylvana regarding her HPV infection: she wanted to know how she could protect herself from future HPV infections.

B] Talking about Sex: HPV Infection and Sexual Health Negotiation

Sylvana was, understandably, concerned about how she got the genital wart infection.[45]

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[44] A low-risk HPV strain, as opposed to a high-risk HPV strain, is not oncogenic, meaning cancer causing. Strains of HPV which cause genital warts are not thought to turn into cancer (Fact Sheet, National Cancer Institute 2012).

[45] While one might assume that Sylvana got the HPV infection from her boyfriend, this may not have necessarily been the case. She may have been the carrier without initial symptoms and the one to transfer it to her boyfriend. HPV is a complex virus and

Having had only a few sexual partners helped narrow down the source she felt. Sylvana explained:

> Well, my previous sexual partners were all virgins[46] so I knew it was very easy for me to bring it down from whom I had it right? So it was clearly from my boyfriend and I talked to him about it and I told him clearly that it was from him. That being said, I don't know if my sexual practices have changed because there is not much that you can change in relation to this diagnosis.

When speaking about getting HPV from her boyfriend, Sylvana brought her narrative to the issue of relationship fidelity, a concern for many students (and most of the women interviewed for this project) because it exposes how vulnerable their sexual health is. Students feel susceptible to contracting STIs and do not know how to mitigate this feeling. Sylvana gave her perspective:

> Even though – our society is so – we are trying to technologize everything and to make everything medicalized and in the end it all boils down to social structures and communication. All sexual transmittable diseases, I think that the first step to preventing them is communication between partners and equal involvement of both partners in awareness of their risks and just checks ups and things like that, like knowing your status related to various diseases and knowing your risks and communicating with your partner. So I think that even though the medical institutions are trying so hard to detect it and prevent it, regardless of how hard they try, if there is no communication at the couple level then all of the attempts are just futile. That is what I think.

When there is a breakdown in communication, as Sylvana put it, women are left exposed. At the time of our interview, Sylvana was undecided as to whether or not she

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infection pathways are not always linear. This often adds to public misunderstandings of HPV.

[46] Virginity as defined as having had no vaginal intercourse does not necessarily preclude contracting HPV. Any form of genital touching can expose someone to HPV (*The Lancet* 2009).

would get the HPV vaccine. Her decision hinged upon fidelity – she felt it prudent to get the shot in the future in the event her partner cheated again. Sylvana explained her thought processes regarding the vaccine:

> I think it really depends on seeing that it doesn't boil down to the money or the risks, I think it boils down to my relationship with my partner, which is really weird because it definitely shouldn't be like that. I should just really think of just getting it. In the end people are just, their natural approach is to just give in to trusting the other and hope to just really have a monogamous relationship, at least most girls would want that probably – most girls I would say. Probably in the next two years if I find that I can rebuild my confidence in my partner and then probably I won't get it but if not, then I guess I'll get it. So in the end it just depends on my relationship rather than any other factor.
>
> It's actually really good that you are doing the social anthropology side. I think that in the end this whole HPV thing really, really should come down to, I think how much people talk to each other in a couple. I think that would make such a tremendous difference in the spread of the virus. So I think that just worldwide people need to communicate more when it comes to sex.

Sylvana's call for more open communication surrounding sex, whether as a couple, among peers or within popular discourse was a common sentiment expressed by students. It is precisely such open communication that was lacking in the Ontario government's school-based HPV vaccination program according to Sylvana. She remarked how an HPV educational campaign was markedly absent from this public health initiative. According to her, a shift in strategy is required:

> The Government should really focus on giving people enough education on sexual communication within the couple while people are in school and from there on when you're an adult. So it is totally up to everybody whether they want to use a condom. It doesn't totally protect but I really believe in that. Even though they are kind of running away from saying it I really do believe condoms

> protect against it, at least some of the – and the female condoms even more than the male condoms because they cover a larger surface area. I think that once you are an adult that's it.

Maya also advocated for the inclusion of HPV sexual education programs in the school curriculum as an integral component, but she felt conversations about sex needed to happen on a societal level as well. For Maya, this should be the starting point as many North Americans are uncomfortable talking about sex, let alone contemplating a range of sexual education programs in schools. This may, however, be in part because sexual education is rarely offered extensively in schools, she thought. As she discussed the circularity of this argument, she was quick to stress that she had not received any sexual education while in elementary or secondary school. Maya described her chats with fellow sexual health researchers in her graduate nursing program:

> Yeah and so, we all talk sort of about our experiences with sexual education like, growing up, what practices they used as teenagers versus the practices we use and how they kind of evolved to that. And I had very unsafe sexual practices when I was younger, very, very unsafe. And I guess I didn't really have any sexual health education and it wasn't because my parents are right wing or anything like that. It was just kind of not talked about. Or maybe I didn't want to talk about it, I probably didn't at the time. I'm sure they tried and I told them to screw off or something like that.
>
> But then I had other friends that never had unsafe sex in their whole lives, which totally blows my mind. But then they had very proactive parents that from an early age were sort of ingraining this stuff into them, like, this is the science behind it. It's not scary, it's not a big deal – this is just what it means. And you know I think if I had, maybe, had more of the science, because I have very much a science mind, I've always studied science, like if I'd had some of that before, I think it could have made me make different decisions, possibly.

In talking about increasing interpersonal and institutional conversations about sexual health education, Maya touched on (as did Sylvana) the vulnerability of women while negotiating sexual encounters:

> But then there's also the layer of young girls not being empowered to make these decisions as well. So, that has nothing to do with education. Like you may right know that having unsafe sex, unprotected sex is dangerous but that you don't necessarily have the power to make that choice in the situation. And so that adds another dimension to it.

This dimension, as Maya referred to it, was a theme that recurred throughout all of my interviews, regardless of whether or not the women were mothers negotiating the vaccine for their daughters, university students contemplating being vaccinated or gynaecology patients being vaccinated in a hospital setting. The theme of vulnerability or lack of power while negotiating one's sexual health is explored in more detail in Chapter Seven.

C] Gender as it Bears upon HPV Vaccine Decision Making

The lack of sexual education accompanying the current HPV vaccine policy in Ontario was not the only aspect of current government programming that upset students; they were, overwhelmingly, annoyed by the gendering of the vaccine. Sylvana, while not pleased with the gendering of the vaccine, offered some of the least intense discussion in this regard:

> My thoughts of the HPV vaccine, I don't – I would have to study a lot more about it to just say, "this is what I think about it," but I think it's wrong just giving it as early as whatever age – 14 is it? Yeah, I think that is the wrong approach. I think that what people should be emphasizing their preventative measures towards is a lot more screening and especially [for] males. There is a huge problem with males because apparently they, like in a lot of sexually transmitted diseases, do not show any symptoms whatsoever. It seems like more so than women because women have a small chance of not showing any symptoms but it seems like in males that they have a better chance of not showing any symptoms and having no clue that they have an infection. So it is actually incorrect at this point to give vaccines to young children instead of funding research to screen people and then funding educational classes in schools where you can tell a child, "You have to communicate with your partner. You have to get screened if you want to start a long term, stable, monogamous relationship and you intend to not use condoms." People really, really have to be aware that their partners have to be screened before they start unprotected sex. Today, this is something that it is pretty much up to the male what happens [referring to condom use]. I think that is wrong as right now everybody is trying to push towards a more egalitarian approach between the two genders.

Sylvana pointed out that in addition to the lack of sexual health education available, men, in her experience, were tasked with the decision to use or not use a condom in a sexual relationship/encounter. This was a troubling trend for Sylvana and one that she would like to see changed. However, altering such a complex socio-cultural phenomenon would be a difficult task, she acknowledged, but one that could be addressed in sexual health education. Thus, Sylvana's thoughts, generally, returned to her central tenet that sexual health education is a must.

Maya was also perturbed by the gendering of the vaccine, but was more forceful in her discussion than Sylvana. Maya felt at a loss as to how to manage the complexity of the vaccine. For Maya it was difficult to resolve the tension between the vulnerability of women negotiating their sexual health and the potential assistance that the vaccine could be in spite of the outright targeting of women – targeting which becomes synonymous with blame when women acquire an STI. Maya elaborated on the dilemma the vaccine creates as it is described in Gardasil® advertising and provincial in-school vaccination programming:

> Well, it's hard. Women are meant to feel, made to feel bad about their bodies in so many different ways. And this is another way in which we're disempowering women to make healthy choices and to take their own health into their own hands by saying like you need this vaccine because you're going to have sex, you're going to get dirty, it's going to make you sick. And so it's putting, yeah, it's so tricky. I think it can be done in a way that it's empowering and can make women healthier but the way it's being marketed as a gendered vaccine is saying that the girls in our society are unhealthy, the girls in our society are intrinsically sexually deviant and are going to get STIs and the boys are not and so here's some way to protect them, protect the virginity, protect the innocence of these girls from getting sullied with sexually transmitted diseases. And that just makes me sick thinking of it that way.

Figure 7 – Gardasil® advertisement targeting young women

Maya was not the only one made to feel "sick" about the gendering of HPV. Amber, a 26-year-old law student was even more outraged than Sylvana and Maya. She is an award-winning student from northern Ontario, and currently enrolled in a university in Toronto. She is the first in her family to attend university and one of the few students I interviewed from a working class background (most students were from middle to upper-middle class families). Amber is particularly interested in feminist law. Amber was visibly upset when she talked about the gendering of STIs, HPV and the HPV vaccine. As our interview progressed, she became more and more agitated – in fact, her anger about these issues was clearly palpable by the end of our time together. Amber had a decided opinion in respect to the gendering of STIs:

> I think it would be associated with the turn of the 19th century. To my knowledge a lot of issues about venereal disease had come up during this period and they were very much associated with women.
>
> Even though as we know today, it takes two partners to start transferring things; in other words, [it takes] male promiscuous behaviour to often transfer STDs and venereal diseases. And certainly it [STIs] is just still, I guess, associated with female, dirty sexual behaviour. STIs are thought to be something that's contracted through "dirty" sexual practices.

Amber elaborated on the gendering of HPV:

> Again I think this has to do with the history of associating certain types of STDs and venereal diseases as coming from women. Even though like as I mentioned the contraction and the spread of these diseases has a lot to do with male sexual behaviours as well. One thing when I was doing the research on the vaccine and HPV, one thing that they said was the reason why a lot of STDs and venereal diseases become associated with women is because oftentimes the symptoms appear on women as opposed, and not so much, on men. And the reason for this being that the vagina is really hospitable for the growth of different bacteria and viruses. And so I guess on a man for instance who has HPV but maybe a very, maybe not a serious strain or something like that, evidence of HPV won't come

> up. But on a woman who has maybe had it for a very short amount of time like she might have signs, visible signs of having contracted the virus.

Even though students exhibited consensus regarding their irritation with the gendering of the vaccine, this annoyance did not lead to uniform vaccine uptake decisions. Some students were so turned off by the gendering of the vaccine – both the in-school programs and the Gardasil® advertisements – and what they perceived as potential vaccine risk because long-term vaccine data does not exist, that they refused to get vaccinated. Others were mildly perturbed by the gendering and also worried about potential vaccine risks,[47] but this resulted in them putting off their decision to a later date. Still others grudgingly got vaccinated, but made it clear that this "choice" was by no means an endorsement of HPV vaccine gendering. As Appendix M indicates, numerically almost two-thirds of the students interviewed decided not to be vaccinated or to delay vaccination decision making (70 percent or 17 out of 24 students). Each of the three vaccine decisions is discussed in turn.

1. Saying "No" to Gendering and Vaccine Risk

As concerned with sexual health as Maya was – this was after all the basis of her graduate training in nursing – Maya chose not to get vaccinated due to the gendering of

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[47] It should be noted that even though students were concerned about potential vaccine risk, or long-term side effects, they were not anti-vaccine. Students, as was found with mothers, did not suggest that people should not get vaccinated at all. Instead, they felt they should be cautious of new vaccines until longer-term research was released.

the vaccine and what she perceived as vaccine risk. Maya explained her position on the vaccine and, as a result, her decision-making rationale:

> I'm really sceptical about the vaccine, particularly because it's mass marketed towards girls, vaccinating girls and women and absolutely no focus on boys and men. And you know it's a vaccine for HPV, it's not a vaccine for cervical cancer even though the strains it targets can lead to cervical cancer. But I just feel that if we actually want to reduce cancer we probably should be vaccinating everyone. I think it is interesting that they're targeting only girls and women because there hasn't been any long-term research on the effects of the vaccine so we don't really know what's going to happen, you know, ten years down the line, 25 years down the line with these women who have taken the vaccine when they were young girls or teenagers or young women. There's just not any evidence, we don't know what's going to happen and I think that's really problematic.
>
> I read recently that at least in the States and some other countries the vaccine has now been approved for boys, I guess it hasn't been in Canada yet.[48] But there's no willingness or feeling like there's a need to promote it for boys and men the way that they have for girls and women. There's no mass campaign to get these boys vaccinated even though the vaccine is available which I think is just crazy and just really telling.

In addition to being unsettled by the marketing of HPV as a women's disease in both Gardasil® advertisements and the Ontario government's school-based vaccination program, Maya was concerned about long-term vaccine risks. She expanded further as to why she decided not to get vaccinated:

> It's just, I mean, not to be like a conspiracy theorist and I wouldn't say anybody is doing this necessarily consciously but what is being said is that it is okay to put women and girls at risk of a vaccine that we are not really sure what's going to happen in the long term or how effective it is actually in preventing cancer,

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[48] Gardasil® was granted approval for use by boys and men up to the age of 26 by Health Canada in February 2010 (CTVNews.ca Feb. 23, 2010).

> but we're still going to really promote it for girls, but we're not going to take that risk with boys. I think that when you look at it with a gendered lens you can see that we are really putting girls and women at risk here and we are not doing the same with the boys. I think that offering it for free is kind of pushing people in the direction of taking it because you know if they don't get it that year then they are going to have to pay hundreds of dollars to get it. So they may as well get it while it's free. So I think it's maybe a coerced choice if it's a choice at all. This seems like not the best situation.
>
> I still feel the vaccine hasn't been properly tested because it hasn't been around for very long, we don't have the long-term data to see what's going to happen with people who take this vaccine. So I'm wary of anybody taking the vaccine. I'm under the impression that the vaccine was really expedited, all the testing processes and there's no long-term data. There are cases of medical intervention for women that have shown detrimental long-term health effects. You know, the birth control pill when it was first put out there was no long-term data, then we found out that people who take the pill for a long period of time have higher chances of stoke. Any sort of health consequences could potentially arise when we're introducing a drug into our bodies.
>
> So I don't know how anybody can expose themselves to a drug that they don't know how it's going to affect them in the long term. I think that's kind of crazy, so I wouldn't advocate for anybody taking the vaccine.

Maya was steadfastly against getting the vaccine for herself due to the gendering of HPV and the vaccine in governmental and pharmaceutical discourses. She was also wary of the uncertainty surrounding the long-term effects of the vaccine. Saying "no" to the vaccine was Maya's way of saying "no" to the gendered risk discourses of the government and pharmaceutical companies. However, she was also saying "no" to women's over-medicalization. Not wanting to take the vaccine was an act taken to protect her health by avoiding, what was in her view, unnecessary risk. Instead, she managed the risk of further contracting STIs by using condoms and not engaging in unprotected sex unless both she and her partner had had "clean" STI testing, meaning tests were not positive for STIs. Additionally, Maya attempted to stave off cervical cancer by getting regular Pap smears, which she arranged every year with her GP.

2. Delaying Decision Making due to Being Put Off by Gendering and Vaccine Risk

While Sylvana was still recovering from the shock of discovering she had genital warts, she was contemplating getting the vaccine. She had not come to a final decision and was not sure whether she would reach a decision any time soon. As she frequently mentioned during our interview, she had "really mixed thoughts" about the vaccine, and she talked about the problems the vaccine presented for her:

> It's definitely an interesting subject. It's very difficult to navigate this debate as a woman who is concerned about these things [her health] personally. But then also, you're trying to balance all the social factors – the government, pharmaceutical, physiological . . . they're really complicated. I think part of my problem [re: decision-making] is that I am so lost in this analysis.

Sylvana balanced worries about her own health and her desire not to acquiesce to vaccine marketing and policy that targeted women without considering HPV within the context of gender relations. Thus, for her there was a tug of war between her individual concerns and the "bigger picture." This bigger picture, according to Sylvana, painted women in a subordinate, needy, and risky position vis-à-vis HPV and this was reflective of her general social location – a position subordinate to men. As Sylvana said, "it's just women who have to make sure that you prevent yourself from getting into trouble or you have to make sure you're taking the pill and that kind of thing to make sure you are not getting pregnant. It's always the woman who has to do those." Sylvana was pointing out that women must take social responsibility for their bodies and yet are blamed for not protecting themselves against pregnancy.

Sylvana's delayed decision making primarily because of the gendering of the vaccine, which she described as patently unjustified, but her perspective was further complicated by her view on pharmaceuticals. Sylvana explained her skepticism of vaccines, nested in her distrust of pharmaceutical companies:

> I don't really trust vaccines because of the fact that they're not really researched – they haven't been on the market for that long. They say they [Gardasil®] have been proven to reduce the risks of HPV. But, with HPV there are so many types of HPV.
>
> So what is it six, 11, 16 and 18 that it protects? Now, four out of hundred, that's four percent – that's huge to even just say that it protects you from HPV. Maybe those are the more prominent ones – you know what I mean, there's not too much information about that, right? Maybe those are the ones that are easier to fight off. Maybe we might get them one day from having sexual intercourse and you just fight them off. But, it's not talked about, right. My boss's niece got the vaccine and she still got warts. That's why I don't really trust vaccines. It's just my personal feeling, especially when I hear stories like that. It's not really proven. I don't know if it's true what the media, or what was in the news about girls getting sick from it [the HPV vaccine]. I don't know if someone died from it or if they made that up, I don't know. I also think about the example of birth control pills in the sixties and they had such a high level of hormones in them that they were making women quite ill. They weren't tested and we weren't sure what was going to happen and some women did end up dying because of it. It just seems to be a repeat of history – all of these things that doctors and scientists concoct to help women and to fix women and to save women and, ultimately, they don't know what it's actually going to do to women.
>
> I don't like putting stuff in my body that I don't know exactly what it is and what it does. What it essentially is, I get it, a cash grab by a pharma company. They're in the business of selling you stuff that you don't necessarily need.

Not only was Sylvana skeptical of the necessity of the HPV vaccine, she was wary of the benefits of the vaccine considering that it covers four out of a 100 HPV strains. For Sylvana, claims that the HPV vaccine protects women from cancer were an overblown marketing strategy.

It is important to stress that students who delayed making a decision were deeply conflicted about the vaccine. Balancing individual health needs with their distaste for the overarching negative messaging concerning women that is attached to the vaccine – both in pharmaceutical advertising and Ontario government policy – was a difficult task indeed. They could not reconcile these two aspects of their decision making. As Sylvana said, "It's a hard kind of choice to make. But at the same time, how stupid would you feel if you ended up getting cervical cancer and had decided not to get vaccinated. I have mixed feelings so it was why I've held off on getting the vaccination."

3. Saying "Yes," but with Strong Reservations due to Gendering

As my interview with Amber was winding down, I was surprised to learn that she did indeed get vaccinated against HPV. Amber's decision was a bit startling considering how passionately she spoke out against the gendering of STIs, HPV and the vaccine, but also because she had condemned the vaccine a year earlier in a blog entry (which she brought along). The blog post follows:

> January 10, 2009
>
> Hello Everyone! Happy New Year!
>
> Today's entry is a rant (and a serious one at that)! To all my women readers out there: don't get the HPV vaccine! Seriously, this is just a grab by big pharma to target and stigmatize women for a virus that has little chance of actually turning into cancer. That's right – HPV does not necessarily turn into cancer. Don't buy into the hype. Our bodies don't need to represent disease. We are not the bearers of ill health and "dirty" viruses. Resist this continual characterization of women by saying "no." Say "no" to this egregious portrayal of women and big pharma profits.
>
> Please give some thought to HPV vaccination – there is more than there appears to this story. There's no cervical cancer epidemic and no need to inject women's bodies with a drug that has had little testing. Just say "no"!
>
> Yours in earnest,
>
> Amber[49]

Amber's blog entry and her decision to be vaccinated seem incongruous. However, the inconsistency points to the complexity of vaccine decision making for women. Amber's decision is not necessarily a reversal of her position on the gendering of STIs, HPV and the vaccine, but reflects the theme of sexual health vulnerability, discussed by Sylvana and Maya as described earlier in this chapter. Amber outlined what spurred her to reconsider getting the vaccine after posting her blog entry:

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[49] The blog text has been paraphrased as it can be found on the web and may be used to identify Amber.

> Okay, so I have a problem, as I mentioned, with the vaccine even though I got it. I fundamentally have a problem with it because the way it's being marketed towards girls stigmatizes girls' and women's sexualities as being the source of the problem – it puts the onus on girls. Just like when you look at, on having responsible protective sex, again a lot of the onus is put on girls to be sort of the arbitrators of sexuality so that they have to monitor their partner's behaviour and make sure to take on that responsibility of being responsible for both her and her partner without attributing very much responsibility to the man who is involved in the sexual relationship.

Despite Amber's strong reservations about the social consequences of vaccine marketing and policy, it was personal experience which brought about her change in decision making. Learning that a friend had contracted an HPV infection, Amber conducted research on HPV:

> The only reason why I guess I've gained a bit more knowledge about HPV was because of my friend. So before I had the vaccine, I went home [from my doctor's appointment] and I went online and I did some research and it told me some more information HPV, which I guess is good to know either way, regardless of the issue of the vaccine. But one thing that I found was it's very difficult to prevent the contraction of HPV when your partner has it. And they were saying that even with the use of condoms, HPV can still be contracted. And I guess that's probably because the virus itself doesn't exist explicitly on the reproductive organs that are, I don't know, I guess the ones that are used orally or penetratively. I guess, the virus probably exists on other parts of the skin that come into contact during sex. So with that knowledge (laughs) and I mean another thing that I had read is that throughout a person's lifetime I think there are like 70-some different strains of HPV, is that the number? [I informed her that today research indicates there are over a hundred strains[50]].
>
> Having seen my friend going through having HPV I think it's a pretty terrible thing to go through and it affects I guess who she chooses as a future partner, she's a single woman, right. So it's going to affect how her relationships end up

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[50] While different publications list different numbers of HPV strains, generally, HPV is reported as having over a hundred different strains (Society of Obstetricians and Gynecologists of Canada 2012).

> unravelling and that sort of thing and whom she meets. I mean a world without HPV would be nice. But I guess my own concern about my sexual health outweighed any of the potential problems that might come with it. And so, which is why I decided to get it.

Students like Amber are actively conscious of the societal challenges the current, gendered HPV vaccine policy and marketing in Canada bring, but ultimately their own sense of sexual health vulnerability takes precedence over these misgivings. Witnessing the conflict the decision to get vaccinated brought Amber, the complexity of vaccine decision making was made abundantly clear to me. The influence of adverse HPV experiences relayed by friends, family and colleagues served as a strong motivator for women to get the vaccination.

Conclusion

Interviews with students were emotional and intense exchanges. The pain, shame and anxiety attached to having an STI and the few appropriate social channels through which to express these feelings and experiences had clearly taken a toll on the young women interviewed. Students wanted to reframe how STIs were viewed in society. Instead of being considered a traumatic event, students wished that HPV infection could be positioned as part and parcel of a regular sexually active life. As HPV infection cannot be prevented, most sexually active individuals will contract a strain of the virus during their lifetime. Thus, they argued it is unnecessary to level stigma. However, at the same time, students such as Sylvana, felt they were vulnerable to catching STIs from unfaithful partners. Sylvana delayed decision making to determine if her boyfriend would be faithful to her in the future, after she discovered he had cheated on her. As such, students were concerned about not being able to successfully negotiate their own sexual health in their heterosexual relationships.

Overall, students called for more open communication surrounding sexual activity, whether it was as a couple, between peers or within popular discourses. Many students remarked how an HPV educational campaign was absent from current in-school vaccination programming for grade eight girls. Maya advocated that sexual education be an integral component of school curriculum, particularly when the HPV vaccine is offered in a school. Students wanted to increase interpersonal and institutional conversations about sex.

Additionally, students were generally outraged at the gendering of the vaccine and this directly influenced their vaccine decision making. However, vaccine decision making is complex and this was not the only factor influencing negative vaccine uptake as the majority of students chose not to be vaccinated or delayed making their decision. Those who chose not to be vaccinated were angry with the gendering of the vaccine, but were also concerned about potential long-term vaccine side effects. As the vaccine was relatively new, no long-term studies regarding the vaccine were available and the potentiality of the vaccine itself to bring forth risk was too big a chance to take. Those who chose to be vaccinated did so because they knew someone who had contracted cervical dysplasia, which required medical intervention. These inoculated students wanted to avoid undergoing the same stressful and devastating experiences that friends and relatives had undergone. However, the decision to be vaccinated did not mean that students like Amber were not concerned about the social impact of the gendering of the vaccine. Amber was acutely aware of increased stigma being leveled against women who were infected with HPV without the same critique being directed at men, but she deemed that mitigating her sexual health vulnerability through vaccination was a higher priority.

CHAPTER SIX - Pre-Cancer Experiences: Containing HPV Through Negotiating Cervical Dysplasia Treatment and Opting to Vaccinate

Risk – n. 1. a chance or possibility of danger, loss, injury, or other adverse consequences. 2. a person or thing causing a risk or regarded in relation to risk. [COED 1999:1244]

The dangers are only too horribly real . . . this argument is not about the reality of the dangers, but about how they are politicized. . . . Starvation, blight and famine are perennial threats. It is a bad joke to take this analysis as hinting that dangers are imaginary. [Douglas 1992:29]

Introduction

For the mothers interviewed, HPV infection was an emerging concern – a potentiality for their daughters. For the students interviewed, while frequently having been infected with HPV in the form of genital warts, it was temporary; HPV infection was an unpleasant experience but their HPV infections did not persist in the long term. However, the patients[51] at the HPV vaccine clinic often had recurring HPV infections, which manifested in the form of cervical dysplasia, and the subsequent need for

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[51] "Patient" is a highly contentious label for this group of interviewees, and the use of the term is not meant to invoke the notion of an individual who is a passive recipient of health care. Rather "patient" is used in the sense of an active and heterogeneous category of individual who helps shape their experience(s) in the clinic. See the editorial of *Social Science & Medicine* 62 (2006) for a further discussion of ways in which "patient" can be framed and interrogated.

colposcopies, biopsies and LEEPs. Their sense of cancer risk had a different frame of reference than other interviewees – they had been engaged with cancer risk in the past, were in contact with cancer risk in the present and were waiting to see if cancer risk would reappear in the future. Patients with frequent cervical dysplasia presentations are in a liminal, pre-cancerous state. They are not deemed healthy, but nor have they been diagnosed with cancer. They are at-risk for cancer, but this risk may never materialize, particularly if they undergo interventions to remove the pre-cancerous cells.

This chapter focuses on how patients' conceptualizations of cancer causation shift with the development of a virally induced cancer, their experiences with cervical dysplasia diagnosis and treatment, and HPV vaccine decision making. Patients talked about the difficulty of preventing HPV infection and instead looked to contain HPV. HPV vaccine decision making among patients was shaped by their experiences with cervical dysplasia. This being said, patients had a tempered view of the vaccine and its effectiveness, especially given their medical histories.

A] Shifting Perspectives on Cancer and Cervical Cancer

Rebecca was the first patient interviewed at the clinic. Although Rebecca did not blurt out her HPV-related anxiety like many of the students, her experience with cervical dysplasia was emotion filled. This became evident as the interview progressed and Rebecca recounted her ten-year journey with cervical dysplasia. We began our conversation with the first interview question (see Appendix E for the interview schedule) by talking about what causes cancer in a general sense. Rebecca explained her perspective:

> What I find with diseases in general, it's a bunch of factors that come together that cause the disease or what have you. I just want to say with cancers, sometimes I think it is related to stress levels and sometimes more stressed people are more likely to get it and other times it is related to plastics, because I know heating plastics can be bad for your health.
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> Everything seems to cause cancer, doesn't it? It seems to be overexposure to certain toxins or radiation or genetic factors. And, sometimes it is just bad luck.

Jennifer, an outgoing 40-year-old senior human resources manager who made a point of amiably chatting with both clinic staff and nurses on her visits, came to the vaccine clinic on a rainy summer day. Jennifer referred to cancer as an omnipresent "living organism" that is part and parcel of daily living. For Jennifer, like Rebecca, cancer derives from a multitude of risks:

> Just something that our body produces naturally and is part of the society that we live in. I think we fight cancer daily and that our immune system is affected by sleep, nutrition, any number of factors and that can influence whether or not we are able to fight it. Also, obviously, there's genetics and there's predispositions, but that's my view.

Jennifer's statement reflects a sense that risk is ever present.[52] These factors that increase risk – not enough sleep, food that is not healthy and our own family history of

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[52] This risk society type of thinking is precisely what Colleen, a mother, was critiquing in her interview. This points to the vastly different perspectives on risk that manifested between interview cohorts.

disease – present as stressors that must be continually negotiated in our “battle” (Sontag 1999) against cancer. The theme of multi-causality (Sontag 1999) is also present in Kathryn’s narrative. Kathryn, a 32-year-old urban planner who works for a municipal government located in a suburb of Toronto, explained:

> To be honest with you, it’s just the world we live in. Sometimes I think it’s very genetic. It’s just something I think that you can’t prevent necessarily. They are cells that have gone bad in your system, pretty much. You can’t always prevent it. You can prevent some, but not others. This is one, obviously, good example – getting the HPV vaccination helps reduce the risk of cervical cancer. There are a lot of things you can do, like smoking doesn’t help, the two of them go hand in hand. Nasal rim cancer is also an example of smoking and cancer – it is pretty common, smoking makes it more likely, so there’s a link there.

Zoe, a 30-year-old high school teacher and the only Franco-Ontarian interviewed at the clinic, also talked about how the multiple causes of cancer are simultaneously within and outside of one’s control:

> I guess my first impression would be that there are cells already in their body that would be affected by a certain virus or condition in their life, but my understanding is that everyone has cancer cells in their body and it just takes certain things to make it come forward. My other understanding for cancer is that there are so many different types of cancer, you can’t really know why you get it or how you get it, but it’s just … your immune system breaking down, it could be the part of the world you live in or it could be what you eat and this virus kind of attacking those conditions.
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> I am thinking stress, maybe smoking might be something, maybe bad diet, if you live in a part of the world where there isn’t access to health care, your family might have a history of a certain type of cancer that might trigger it as well. So, why people get cancer, I have always attributed it to a bunch of varietals, a bunch of different elements and then also how their body is behaving.

Rebecca, Jennifer, Kathryn and Zoe juxtaposed seemingly incompatible concepts in their narratives: the first being that preventing cancer is within your control, that the risk of getting cancer can be reined in by lifestyle choices;[53] and the second, that cancer risk as a polyvalent "thing" cannot be avoided, being brought on by, for example, hereditary and environmental factors. For patients, cancer was an "invasion" from the "outside" (Lupton 1994:58), but could also stem from within – you could bring it on yourself. This double discourse echoes findings by Sontag (1999) and Lupton (1994) and other social scientists (see Balshem 1991; Hallowell 2006; Lochlain Jain 2007; Matthews 2000; Potts et al. 2007; Potts 2006; Sered and Tabory 1999). Patients' cancer causation narratives reflect themes already found in existing literature; however when they talked about cervical cancer specifically, a shift in their thinking about cancer causation and risk occurred.

Rebecca explained that cervical cancer stems from a single factor: "Well it's caused from a virus that is sexually transmitted and for whatever reason, I don't know why, but it attacks the cervix. The root cause is HPV." For Jennifer cervical cancer develops "because we have cervixes. For cervical cancer, specifically, I believe it is HPV, which is transferred through unprotected sex. I believe that's the main reason, but it does seem

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[53] Attributing cancer to lifestyle choices reflects neo-liberal notions of health whereby individuals are tasked with maintaining their health, absolving the state of responsibility in providing such services as pollution-free water, adequate housing and accessible health care to the underserviced (Lupton and Petersen 1996).

to come later on in life."[54] Jennifer was not being glib in her response, but wished to point out that being a woman puts one at risk for certain gender-specific diseases and in this case HPV targets the cervix. Kathryn talked about how her cervical dysplasia experiences informed her understanding of what causes cervical cancer:

> Well, what I would have said a year ago is that you just develop it. Some people have a chance of developing it because maybe their grandmother had it or it just happens to be in their genes. I have since learned, in the past year, that you increase your chance of getting it because of HPV infection and I learnt about that, the majority, through television to be honest through the TV ads. The Gardasil® ads and from there I had an abnormal Pap test and from there, I started to realize that it may or may not be because I have had an HPV infection. I have had a couple of abnormal Pap tests. So, I put my abnormal Pap tests together with the messaging I had been getting from the TV about Gardasil® and started to think, "okay, there is a connection here."

It is troubling that Kathryn learned more about HPV and cervical cancer from television than her GP, from whom she received the results of her abnormal Pap test. Unfortunately, as Kathryn's example illustrates, patients (and the students interviewed) did not always receive adequate HPV-related information from their GPs when such information would have been helpful in making sense of an abnormal Pap test result. Zoe also received differing HPV-related information from various medical professionals:

> Well, I have to say I have been wondering if we are getting it more now than we used to or is it because now we have the technology to find out about it before it

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[54] HPV is not necessarily transmitted through unprotected sex. Condoms do not stem the spread of HPV because it is contracted through skin-to-skin contact and not fluid exchange.

> turns into cancer? So, I am not sure if people are getting cervical cancer more than they used to or if it's that we have come to the realization that it is more common or not. I have to say what I was warned about when it comes to cervical cancer are factors than can really contribute – they are stress, smoking, low immune system, and I think these are three main factors I was told about. Different nurses and a few doctors agreed on these factors, I have to say, though, that it varies a lot the different information I have been getting from different hospitals and nurses, doctors. But, that seems to be what they all agree on: stress, smoking and immunity.

It is interesting to note that in Zoe's narrative, nurses and physicians attached generalized notions of cancer causation (as stemming from multiple sources) onto cervical cancer, while patients linked cervical cancer with one cause, HPV. Because patients equated cervical cancer directly with HPV – a singular, outside agent – it would make sense for them to link cervical cancer prevention with avoiding HPV infection. This line of thinking was, however, more of a theoretical prospect than a practical reality. Patients did not generally think HPV infection could be avoided unless one abstained from all forms of sexual relations. Kathryn explained, "Basically, even if you use a condom, you can still get the virus. So, I mean from that standpoint, I guess to try and avoid your risk altogether you would have to be – you would have to not have sex. But, I don't see that as a feasible option for most people." Zoe noted that HPV could be contracted through oral sex and touching so, "anyone can get it and anyone can have it, but it doesn't always present with symptoms." Rebecca looked for other ways to manage cervical dysplasia, as forgoing sex was not an option for her:

> From what we know so far, it's sexually transmitted, so abstinence would help you not get it. Other than that, I don't think there is a way to prevent it. So many people are carrying it right now, there is a high risk. So, you'll end up getting the

> virus and some people will get cancer and some don't. I, myself, I already have HPV, so what I am trying to do is keep my immune system up, so I don't run into anything big.

Rebecca's approach was not about HPV prevention, but "containment" (Douglas 1992). For Rebecca, contracting HPV was inevitable, however she hoped to lessen its magnitude and severity through eating fresh foods and making sure she got enough exercise and sleep.

For patients, experiencing protracted cervical dysplasia brought the possibility of developing cervical cancer to the forefront of their minds. Kathryn mentioned that cervical cancer was "definitively a possibility. I am more concerned about it, for sure." And, Jennifer was forthright in stating, "I think it is a possibility and I would be naïve to think I would be excluded from that club." When asked if she thought she would get cervical cancer, Zoe reflected on her sexual health vulnerability:

> I probably will get it. I don't know – it's always those who are not promiscuous that get bitten in the ass. I don't know how to explain it. It's just a karma kind of thing. I hope not, but I have always been so paranoid about getting pregnant and HIV or so forth. You know, my ex-boyfriend was not a decent human being. I feel like I am going to pay the price for him in some way, shape or form.

Patients feared that a sexual partner could infect them with HPV, and that it would eventually lead to cervical cancer. Patients felt that prevention efforts could never be full proof, as Rebecca stressed, "I think you can reduce the likelihood, but I think people can be unlucky and get it." Even though patients viewed cancer and cervical cancer causation differently, they expressed an overall sense of "fatalism" (Drew and Schoenberg 2011) about cancer and cervical cancer. But this fatalism did not prevent patients from regularly engaging in Pap testing and receiving the HPV vaccine. These forms of self-care (Foucault 1988) provided a measure of control for patients in a situation in which overall avoidance of cervical cancer was thought to be impossible. Self-care made them feel a little bit better when, in their view, nothing could be done to avoid HPV infection. Patient self-care merely provided psychological relief – these strategies were attempts to control what they could because they could not mitigate HPV infection risk. This approach to risk management differs from Lupton's (1999b) conclusion about pregnant women who control pregnancy risks by engaging in pre-natal care and testing.

B] Cervical Dysplasia Diagnoses and Treatment Experiences

Conversations with patients tacked between the topics of cancer, cervical cancer causation and risk, and their actual cervical dysplasia experiences. While patients exhibited the same anxiety students demonstrated due to their HPV diagnoses, the emotional undertone of patient interviews was different. Patients were weary and tired as the constant schedule of Pap re-testing, colposcopies, biopsies and LEEPs had begun to wear them down. Prolonged cervical dysplasia had put patients on a treadmill and they were never sure if or when they would be able to step off of it. Interviews provided a rare moment of pause for patients. Not only were patients able to speak in quiet rooms away from the hustle and bustle of the hospital, they were able to take a break from appointments and procedures in order to talk about their experiences.

Rebecca spoke about her first experience with abnormal Pap test results and being assigned a cervical dysplasia grade:

> I had an abnormal Pap smear – that's how I found out about all this. The abnormal Pap tests started almost ten years ago. It just started slightly abnormal and I didn't know what that meant. And, then it went a little more abnormal. There is a scale of being abnormal, so I have been treated along the way, so it doesn't turn into anything cancerous. So far, there has been a lot of monitoring it and a biopsy to see if there were any kind of cancer cells. And, there weren't, so that was good. Recently, I just had a series of LEEP treatments. It's a pain in the butt. You now, it's constant, on-going. You wonder if you are going to get the phone call that it's *really* abnormal this time and what that runs into.

Jennifer, as did Rebecca, required further intervention beyond Pap re-testing. Jennifer stated of her diagnosis: "It's obviously never pleasant to hear news like that – that it is abnormal and could lead to worse stuff"[55]. While often considered unpleasant, Pap testing was not thought of as an ordeal. The same, however, cannot be said for procedures such as colposcopies and the LEEP. Jennifer talked about her abnormal Pap results, the stigmatizing treatment she experienced from her GP upon diagnosis[56] and her colposcopy:

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[55] Throughout interviews patients used the word "abnormal" to describe their Pap test results, which mirrored medical terminology. As such, abnormal appeared to be the new normal for patients.

[56] Jennifer did not receive her initial abnormal Pap smear diagnosis at the hospital where fieldwork was conducted. Not one patient reported experiencing disparaging remarks from hospital staff.

> It was disappointing. I mean it was really upsetting. I felt unclean, I felt targeted. In fact, when I first had the procedure, when I first had a Pap and I started to encounter abnormal cells, you know my boyfriend at the time was with me. We had just started seeing each other seriously and I said what can we do to prevent him from getting it or something and the doctor said something like, "Well, you can always get another girlfriend." I am deadly serious that she said that and I will remember that forever. I felt pretty bad, actually.
>
> Colposcopies are not fun. Fear. Pain. He had to take a biopsy and I didn't have any Advil® or anything and, of course, they always show it on the monitor, on the screen. So, I actually got to see my cervix being cut open – without any anaesthetic, so that was kind of ugh. Having a piece of your cervix removed while watching it was kind of ugh. It was a live camera.
>
> This is why I want to do this study with you because my experience has been ugh. I am glad that I am over it now. Thank God I escaped! I felt like there is a stigma. Even if they say 80 percent of sexually active people have HPV. When you yourself have it and it has been identified, you feel like a pariah and, you know, people don't let you forget it – especially the medical community. Obviously, that doctor or nurse, maybe, she was having a bad day – I don't know.

The attending physician used video technology during the colposcopy to project the procedure onto a screen, broadcasting the procedure in real time. This is generally done for teaching purposes, but it greatly disturbed Jennifer. Not only did the biopsy, which was performed during the colposcopy, hurt (she had not taken pain medication in advance), she also witnessed the cutting and removal of cervical tissue on the screen. Jennifer used the term "ugh" multiple times in the interview. Although this term may at first seem to have the connotation of "bland" or "unpleasant," in the context of her narrative "ugh" stood for distress and being upset and emotionally strained.

Not only did patients experience pain and anxiety, but an overall feeling of distress during their procedures. Kathryn provided similar details regarding her recent colposcopy:

> I had abnormal cells back in January 2009. I went back six months later, to my normal GP to have it done again and the cells were gone. So, I was confused as to what happened. Did they just disappear? Then I went back six months later, which would have been my yearly Pap test and the cells were back. I was sent to have a colposcopy. My doctor very much played it down, saying it's no big deal. The doctor said, "It's just like a normal Pap, they are just going to snip you a little more and it's fine." But, having a colposcopy was not fun. It was not what I expected. It was a little more difficult to deal with than I had anticipated, than my doctor had told me. What I didn't expect was that I was going to bleed for a week afterwards. I didn't know. The doctor said you might bleed for the rest of the day. Not me – I bled for the rest of the week. I got this overall icky feeling – like I needed a shower. I was originally going to go by myself and I am glad that I didn't. I brought my mom with me, so she could drive me home. So, yeah, I didn't feel prepared for what was going to happen.

Kathryn had the urge to "cleanse" herself after a colposcopy which signifies a need to purge oneself of an emotional and anxiety-ridden event. It may also indeed be a way to rid oneself of the virus and its accompanying abnormal cells. Additionally, Jennifer used the word "unclean" when describing how she felt in response to physician judgment. To choose a word like "unclean" may appear to parrot dominant discourses about STIs which focus on "dirty" and "infected" individuals, but Jennifer was verbalizing how the physician pointed out that she was different from those who did not have an STI-related infection. Physician choice of words and attitudes towards patients leaves them no choice but to try to reassert their morality and self-worth.

Zoe's experiences echo those of other patients; she too had an anxiety-ridden colposcopy. Zoe spoke at length about undergoing a LEEP:

> It was a painful and stressful experience. At the beginning, when I first had my abnormal results with the Pap test, I was crying because I thought I had cancer. I knew nothing about HPV and I didn't know how many people have it and how common it is. At the beginning, I was stressed out about it because I knew nothing about it. I went in for a colposcopy and it wasn't really pleasant, it was more unpleasant than painful, I guess. Afterwards, I had a LEEP procedure done – about six months later – and that was extremely painful. So I guess, after that first week, everything else that is associated with going to the doctor for a Pap test, colposcopy or anything to do with HPV has turned out to be a really stressful and painful situation, unfortunately.

At the time of their interviews, Kathryn and Zoe were waiting to take part in post-colposcopy and post-LEEP Pap re-testing in order to find out if they were cervical dysplasia free.[57] During this period, Kathryn and Zoe were suspended in a liminal, pre-cancerous state. This is a unique state medically speaking – they are betwixt and between being well and sick. They have not been diagnosed with cancer but with pre-cancerous symptoms that if left untreated could eventually develop into cancer. As Lupton, drawing on Douglas, states (1999b), being in an "in between" state is generally "dealt with by societies as impure, contaminated and risky to their integrity" (78). The anxiety that women expressed at being in a liminal state was palpable, and waiting for Pap re-testing results contributed to their worry. Moreover, there was a sense of isolation if people in one's social or familial circles were not comfortable talking about

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[57] Having cervical dysplasia is not a straightforward or constant diagnosis. HPV is most certainly an indeterminate and fuzzy virus. HPV can be transient and differing stains can appear at different junctures. As a result, patients can move in and out of being at risk for cervical cancer.

STIs. As Kathryn mentioned, “I can’t talk about it with anybody.” Jennifer also stated that she did not receive much social support throughout her ordeal, but felt comfortable taking part in our interview because her last few Pap tests had been fine:

> It is isolating – you don’t want to tell anybody. I can only talk about it because I am rid of it. I wouldn’t want to tell anybody if I had it. It’s like you have the “couties” or something. It’s like I did it to me, but it didn’t occur out of the ether. It got passed along and it’s not because you are a “ho” or something. Well, then everybody is a “ho.” It was horrible.

Patient social isolation was augmented by the fact that they were not seen by society at large to be susceptible to the virus. Patients are not the target of HPV vaccine marketing; this advertising is aimed at grade eight girls and their mothers, and at university-aged women. Mass media articles are also not written about women in their 30s and 40s with protracted HPV infections. Furthermore, patients do not benefit from a government-oriented vaccine subsidy. As a result, patients have been left out of popular and policy discourses concerning HPV.[58] Patient experiences are not simply a topic of public discussion. Patient bodies are “abject” (Kristeva 1982:1) – bodies at the margins of HPV and HPV vaccine-related discourses.

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[58] Since conducting fieldwork, Health Canada has extended the recommended age of vaccination to women up to 45 years of age (Merck Frosst April 26, 2011 press release). This change has not been reflected in Ontario-based HPV vaccine policy.

C] HPV Vaccine Decision Making

As all patients received the vaccine, it is not surprising they were strong supporters of vaccination in general and thought that getting the HPV vaccine was a good idea. Jennifer described how it felt to get the "shot," the term patients and clinic staff used to refer to the vaccine:

> Well, the actual shot hurts. The first doctor, she warmed up the shot, so that when she administered it, it didn't hurt as much being plunged in, I suppose. But, the second nurse, just kind of plunged it in cold. It actually hurt. So what – I don't care. I mean if it prevents cancer, who cares, right? The shot is great – it's just a vaccine. I'm happy there is one. I am really glad there is one. I'm glad we have that option. But, I think probably for most folks the price tag would turn them off.

When asked if they thought there were any risks associated with the vaccine, both Rebecca and Jennifer answered an emphatic "No." Rebecca explained her reasoning behind getting the vaccine, "For me, it was just to take advantage of what all is available today and to be able to reduce the risks for myself." Jennifer's decision to get the shot was directly related to her cervical dysplasia experiences as she explained, "After that LEEP procedure, you know, I really needed to take every step possible to never have to deal with any abnormal cells possible." However, Jennifer waited a period of time before proceeding with the shot due to the cost:

> I finally decided to . . . I mean, I asked my health coverage because I noticed it wasn't covered on our plan and I asked to see if it would be covered. It wasn't broadcast and it wasn't in the literature, we had to specifically ask if this was covered and they said it was, but it was not covered electronically. You have to

> mail it in. It is a bit of a pain to be reimbursed for it. They don't make it easy.

Jennifer was fortunate to have private health insurance that covered the vaccine. Overall, 45 percent of patients had private health insurance which reimbursed all or some of the vaccine cost, 40 percent did not have private health insurance so they had to cover the cost out-of-pocket and 15 percent were not sure if they had insurance or if their insurance would reimburse them for the vaccine (see Appendix M). The percentage of patients holding some sort of private health insurance is lower than the provincial average of 62 percent (Luffman 2005). Patients were more likely to have private drug coverage if they were employed in high-wage, unionized, full-time and/or permanent jobs. As my interviews took place in the latter half of 2010, patients were still impacted by the 2008-2009 financial recession and many were working in temporary contract positions.

Kathryn was also strongly in favour of the vaccine and passionately shared her thoughts:

> Well, I am pleased I can have it. Not happy to have three doses of it, but if that is what you have to do, that's what you have to do. I wish I had the opportunity to have it when I was younger, before I became sexually active. I think that a lot of people aren't aware of it or they don't know why people get it or why 13-year-old girls are supposed to get it. Particularly people my age who don't have children, who are not being told by their school or public health, you know, "Your kids need the vaccination." So I'm 32 and in my group of friends I have, between 25 and 35, really don't know much about it and, subsequently assume they don't need to get it. I think that it should be, knowing what I know now, it should be on a list of vaccinations that everyone should get. You know, I have

> my vaccination card from when I was a baby and I hope that one day it will be generic enough to be on that list because if it prevents you from developing cervical cancer or getting genital warts, why not.

Kathryn's passion, though, was not without worry regarding the risk attached to the vaccine. Unlike Rebecca and Jennifer, Kathryn ruminated about the vaccine's possible downsides:

> I worry that the vaccination hasn't been around for long enough for me to know if it is going to affect me when a couple of years roll around. That's why I think a lot of my friends aren't getting it. They assume, "Well, the vaccination hasn't been around very long, so we don't really know what the effects are going to be." What if it makes you infertile? You know, there are long-term effects we don't know of. So these things sort of worry me. It's not like the vaccination has been around for 70 years, but through the research I have done and the people who have given me the vaccination and the physician who did my colposcopy that those worries – that I don't have much to worry about.

It was common for patients to recount how their GPs had suggested that they were too old to get the shot. The disappointment and frustration of not being fully informed by their GP was a recurring theme among patients. Kathryn spoke about experiencing cervical dysplasia at the same time that the Gardasil® advertisements hit the media and how she asked her GP about getting the vaccine. Kathryn described a visit with her GP:

> Now, I will say I asked my physician once about getting the HPV vaccination when it first started coming out on television and I said, "Should I be getting this?" and he said, "No, it's only up to 26". So, I said, "okay." I wished that my doctor was more aware because now it is two years later and I'm now just getting the shot, Maybe, in the last two years is when I got HPV. I don't even know how I have it, but maybe I could have prevented it had my doctor been informed. Frankly, I'm angry. I am angry he didn't know that because he does

> my yearly Paps and it is a common enough issue. He should be more informed about it. He wasn't informed to that level and, in hindsight, I wish he had been.

It was not until many of the patients attended the hospital colposcopy clinic that they realized they could, indeed, be vaccinated. Kathryn described the moment she was told she was eligible for vaccination:

> When I went to have the colposcopy, the physician who did it asked if I had had the vaccine. And, I said, "No, I thought you had to be under 26." She said, "no, that's not true". The people they originally studied it on were up to 26, so that's why they can't communicate about it being over 26 and she wrote me a prescription for it. She said, "If you'd like to get it, here you go. You can get it and I would encourage you to do it." At that point, once I realized I was allowed to do it, even though I am over 26, I knew I was going to get this because I don't want to have a colposcopy ever again. It's really not enjoyable at all and really the primary reason is I don't want to have to do a colposcopy or LEEP ever again, or whatever the next phase is. That's the real reason.
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> I had done a little bit of research about it before and because it was up to 26, I had stopped reading. The moment I was told I was allowed to get it, later that night I went home and I did a little bit of research on people getting it over the age of 26 and it said you can. So, I picked up the phone and made an appointment here. So, it was a quick decision from the moment I was told I was allowed to get it.

As Kathryn explained, the primary motivation for patients to get the shot was to avoid undergoing further Pap re-testing, colposcopies and LEEPs. While patients felt fortunate to be able to get the vaccine, particularly due to its high cost, they were not certain what benefit the HPV vaccine could bring to them as they had already been infected with HPV. As a result, patients exhibited a reserved optimism for the shot – their enthusiasm was more conceptual than pragmatic. Patients were uncertain about the long-term prophylactic benefits of the vaccine, even if it would ward off HPV strains they had not been infected with to date. Zoe expressed this uncertainty:

> Well, I'm not quite sure what to think about it. The reason I wasn't getting it in the first few years that I started seeing doctors was that I had abnormal results. I didn't think that it would help as I already have HPV, so why should I get the vaccine? It's still a little bit uncertain, even yesterday when I went in to do it. My boyfriend said: "I don't know what the point was that we did that or not." I think that we both felt that it might not hurt, so we might as well get it done, but at the same time, we aren't really sure if it will help the current virus that I have. They were saying it might or it might not and will it do anything at all? So, I am not sure.

Zoe explained that it was her gynecologist's repeated suggestion to get the vaccine that convinced her to go through with it. Zoe talked about reaching her decision:

> The past few years that I have been seeing doctors, they have been saying it wouldn't hurt if you get it. They weren't insisting, but it can't be that good or bad to have it done. Last time I saw my gynaecologist, he recommended I get it. So, I thought why not. It's been a few years that this has been going on and I thought it couldn't hurt or it could do me some good.

Rebecca also expressed similar doubts as to the effectiveness of the vaccine, as she has been experiencing HPV-related complications for some time, "Well, I guess that it's fantastic that they have come up with something like this that could save a lot of lives in the future if they are targeting the right people. It's probably too late for me, even though I just went through it." Patients called into question the effectiveness not the efficacy of the vaccine. Efficacy refers to "how a drug works in an ideal situation among highly selected individuals, not about effectiveness, how it works – does it do what it is supposed to do – in the 'real world' among the general population" (Lippman 2010:100). Patients had no doubt the vaccine could potentially work, they just were not sure if the vaccine would work for them with their particular medical histories.

Conclusion

Seeking HPV vaccination is a "transformative" (Polzer 2010:71) act for patients. It works to give them a small sense of control over the uncertainly brought about by cervical dysplasia of many grades and associated Pap test surveillance, colposcopies, biopsies and LEEPs. This sense of control is not the same as the oversimplified empowerment message of the Gardasil® advertisements. These advertisements advocate for a certain outcome from vaccination – the avoidance of cervical cancer – and sidestep HPV as an STI. Patients are acutely aware of the means through which HPV is transmitted and believe that HPV cannot be avoided but only contained. They also do not feel that cervical cancer can be prevented. As such, their tempered enthusiasm for the vaccine was more conceptual than pragmatic. Given their medical histories of recurrent cervical dysplasia, patients were not certain if the vaccine would help them, but were willing to get vaccinated, particularly when the shot was recommended by their gynecologist. For patients HPV vaccine decision making was not a linear cost-benefit analysis focusing on whether benefits outweighed the risks, including potential harm and affordability (see Brewer et al. 2007; Chapman, 2010; Jacobson et al. 2007; Poland and Jacobson 2001; Poland et al. 2009). Instead, motivation to get vaccinated stemmed directly from patients' anxiety-ridden experiences with cervical dysplasia. As such, the high cost of the vaccine did not deter patients from getting the shot. Even though patients questioned whether or not the shot would be beneficial to them given their medical histories, they were willing to give the shot a try.

CHAPTER SEVEN - Women's Productive Re-Ordering of Risk and Gender and Ontological Decision Making

What has emerged from interest in the human body, as it is lived, is a multiplicity of bodies, inviting a great many disciplinary points of view and modes of interpretation. If bodies and lives are historically contingent, deeply informed by culture, discourse and the political, then they cannot be summed up in any one kind of narrative. [Lock and Farquhar 2007:2]

Introduction: Situated Risk and Gender

Women's narratives provide the opportunity to examine the plasticity of risk on the ground. These accounts are what Boholm (2003) calls the negotiation of "situated risk" (158). By examining and analyzing situated risk, anthropologists are able to move between three points: grand theory relating to risk; individual accounts of risk encounters; and the political, social, historical and economic context in which these mediations occur. Situated risk allows anthropologists to "problematize structural dimensions" affecting individual risk negotiation and to offer "nuanced ethnographic" renderings of these experiences (Boholm 2003:158). This goes beyond existing research in other social science fields focusing on risk, which generally zeroes in on either grand theory (see Beck and Willms 2004; Castel 1991; Dean 1999; Giddens 1991; Giroux 2010; Gordon 1991; Ewald 1991; Fox 1997; Petersen 1997; Rothstein 2006) *or* individual accounts (see Bond et al. 2012; Brown et al. 2013; Crighton et al. 2013; Gross and Shuval 2008; Lear 1995; Russell and Kelly 2011; Spencer 2013; Thing and Ottesen 2013; Tuinstra et al. 1998; Walls Dr et al. 2010; Zinn 2008), but not both. Concentrating solely on grand theory leaves out the important human element of risk, and researching only individual experiences, unintentionally reproduces sales/governance strategies. Highlighting individual accounts of risk, without adequate contextualization, reinforces the new public health's concept of "the individual-as-enterprise" (Petersen 1997:198). The individual-as-enterprise tenet promotes one's self-regulation through the notion of "healthism," which emphasizes control over one's health and "posits that the individual has choice in preserving his or her physical capacity from the event of disease" (Petersen 1997:198). The emphasis on self-regulation provides an environment which is ripe for the "privatization of risk" (Lupton 1999a:5). In the new public health, risk is deployed as a central theme through "an emphasis on anticipating and preventing the emergence of undesirable events such as illness, abnormality and deviant behaviour" (Petersen 1997:192-3). Castel (1991) posits that this is a significant epistemological shift that "has led to the replacement of the notion of *dangerousness*, formerly used to designate the privileged target of preventative medical strategies, by the notion of *risk*" (282). Thus, an individual is now signified through a multitude of risk factors. Risk is not conceived of as pertaining to actual events, but the immanent possibility of such manifestations. This shift produces a far more fertile terrain through which to procure and implement prevention programming. In the "individualization of risk" (Dean 1999:133), if a person does not proactively seek out and enact strategies to prevent risk, it is deemed his or her fault for not working hard enough to mitigate risk. In the case of the HPV vaccine it is up to women to protect themselves and their daughters regardless of the fact that men also contract and transmit HPV and acquire HPV-related cancers. Situated risk, due to its grounded and contextual approach, avoids these pitfalls. Boholm herself best describes it:

> By means of analytical categories and theoretical work, the fluidity and the elusiveness of "risk" as it emerges in real life, in contrast to the abstracted models of ideal states prominent in much risk research, is provided with form and substance, flesh and blood, and human significance. [2003:158]

However, as salient as the situated risk concept is to the research at hand, it does not address how gender intersects with risk-related decision making, nor the specific governance techniques associated with gendered risk making (as were outlined in chapter two). As Lupton observes, "the theorization of risk has tended to neglect the insights offered by contemporary feminist theory and the sociology of the body in understanding the links between gender, embodiment, subjectivity and risk" (1999a:7-8). Moore (2010) takes this critique one step further by lamenting that, "among all these strands of research – on health inequalities, the medical profession and differences in health care provision across female groups – one aspect of 'classical' feminist work on gender and health was on the wane: the theorization of gender" (99). When risk-oriented literature does indeed address gender, it examines "women" and treats this static category as a pre-given "fact." This academic treatment "has led to the perpetuation of essentialist ideas about sex and gender – the notion that the former directly and naturally entails the latter" (Moore 2010:100). Examples of such literature still frequent the academic record today (see Crighton et al. 2013; Gross and Shuval 2008).

This research project begins to address this theoretical and pragmatic gap. As such, it has been an exercise in examining both situated risk and situated gender.[59] As is discussed in this chapter, the women interviewed actively engaged in the re-ordering of risk and gender whilst taking part in HPV vaccine decision making, whether the vaccine was for their daughters or themselves. This led women to take part in ontological decision making. Vaccine decision making is not the product of individual rational choice, but social and cultural processes. Women's vaccine decisions were layered into, and a result of, their active and situated experiences with gender and risk. Their situated experiences of (1) doing mothering, (2) doing gender politics and intermittent risk and (3) doing risk outline women's efforts to be good mothers, strong young women merging into adulthood and pre-cancerous patients seeking a "pause" amongst the anxiety of their seemingly never ending cycle of medical procedures. All three modes of "doing" result in specific vaccine uptake outcomes – the linkages between identity making and decision making are layered and non-linear, but strong nonetheless.

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[59] Although, Boholm (2003) does not refer to Lock and Kaufert (1998) in her piece, situated risk and situated gender are issue specific versions of producing "situated accounts" of the "microphysics of power" (Lock and Kaufert 1998:1) as they play out in the everyday realm of HPV vaccine negotiation and decision making.

A] “Still” Moments and Ethical Agency

During their interviews, the mothers, students and patients who took part in the study paused from their daily lives. For the hour or so that an interview took, these women did not answer their phones, take care of a child, tend to home work or participate in a medical appointment or procedure. Our time together was an opportunity for them to exhale and unplug from their daily lives. Interviews can be described as a moment of respite, but the pause experienced during interviews is akin to Stewart’s concept of a “still life” (2005:328). Not only is a still life a moment of contemplation, it is a productive event. Stewart explains, “the word ‘still’ refers both to the state of being at rest and to an apparatus used for distilling liquids – a still” (2005:328). Thus, being still also holds “a promise that a moment of intensity will emerge” (Stewart 2005:329). This intensity surfaced when women reflected on what being a mother, a university-aged woman or a patient meant to them and how these gendered identities specifically intersected with HPV infection and HPV vaccine risk. Mothers and students ruminated on and processed how governmental and pharmaceutical discourses transmitted messages about HPV infection and HPV vaccine risk and then hybridized or rejected these messages. For patients, it was about how they were “living with risk” (Lupton 1999b:68), all the while being excluded from the public discourses aimed at mothers and students. Patients were not, however, removed from the gendered discourse of societal blame when they contracted an STI. Their situation was unique among the women interviewed for they had to meditate the murky and uncertain territory of being labeled pre-cancerous. All the women, nevertheless, demonstrated that their vaccine decision making was not a linear, cost-benefit analysis focusing on whether benefits outweigh risks, including potential harm and affordability. Instead, decision making was steeped in their experiences as women, including previous (and current) HPV infections, what being a good mother meant to them and how they envisioned gender as they mature into womanhood.

Each interview contained much more than just a discussion of the women's vaccine decision making. When taking a pause to be interviewed, each woman created a narrative that contributed to her continually developing sense of self. As each narrative developed, identity was re-inscribed and re-enforced for it was in the thick of the pause that the exterior subject formation of pharmaceutical and governmental discourses and the interior realization/actualization of the self intersected. The pause is what Allen calls an "*inter*subjective (rather than a *non*subjective, whatever that might mean) frame for feminism" (2008:17).[60] Lock and Farquhar utilize the conceptual frame they have termed "living" (2007:2). These medical anthropologists state, "to make bodies a topic for anthropological, humanistic, sociological, and historical research is to ask how human life can be and has been constructed, imagined, subjectively known – in short, lived" (2007:2). Whether one places the generative aspects of narratives in a pause, an intersubjective frame or within the concept of "living" is secondary – what is important to emphasize is what women are doing in these moments. Women are not always

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[60] Biehl et al. (2007:7, 10) also make reference to the term intersubjective. In their volume the term denotes experiences across or amongst a grouping of individuals or collectivities.

portrayed as “doers” or as those who “do,” and in the case of HPV infection and vaccine women are positioned as passive recipients and bearers of disease. Being a “doer” is a term often reserved for men, as Pandolfi discusses in her research of women and their development of self and illness narratives in a southern Italian village (2007:453). As a result, it is important to emphasize that the pause of the interview is a space of doing. Inspiration for emphasizing what women do also lies with Butler’s (2004) work – her well known “doing gender” concept. As per Butler, doing gender is a continual process, not a discrete or concrete bodily motion. She elaborates:

> Gender is a complexity whose totality is permanently deferred, never fully what it is at any given juncture in time. An open coalition, then, will affirm identities that are alternately instituted and relinquished according to the purposes at hand; it will be an open assemblage that permits multiple convergences and divergences without obedience to a normative telos of definitional closure. [2007(1990):22]

It is in the space of the pause that women are actively, continually and complexly negotiating their sense of self while working to secure their health vis-à-vis HPV infection and the HPV vaccine. It involves constantly engaging in acts of self-reflexivity or “practices of the self,” including actions, habits, movements and self-framings deemed to achieve one’s goals of the “good” or “moral” (Butler 2008:27-28). This is what Foucault means when he writes about working towards being an “ethical subject”. When referring to being ethical, Foucault is foundationally speaking of “the kind of relationship you ought to have with yourself, *rapport à soi*” (1997:263). When engaging in this relationship with oneself, we are creating our own “telos,” or our own set of codes for maneuvering daily life (Foucault 1997:265). Scripting one's telos is an exercise of invoking power, no matter how fleeting or limited it may be. However, when writing one's telos one does indeed draw from the social environs. We do not make and re-make our codes in a vacuum, and in the era of the new public health, individuals are encouraged to actively develop habits and practices centering on self-regulation through "healthy lifestyles" (Nettleton 1996:44). This can constitute individualized behavior, such as refraining from smoking, moderating drinking, being on low-fat diet regimes and limiting the number of sexual partners (Moore 2010:101). What happens in one's surrounding environment matters; even if one is reacting against a particular norm, such as what is deemed "healthy" behaviour, this norm is still very much present in the revised telos. Butler expands upon the creation and enactment of micro scripts within the overarching landscape of macro scripts:

> Ethical agency is neither fully determined nor radically free, but is one whose struggle or primary dilemma is to be produced by a world even as one must produce oneself in some way. This struggle with the unchosen conditions of one's life. A struggle – an agency – is made possible, paradoxically, by the persistence of this primary condition of unfreedom. [2008:28]

It is in the negotiation of this unfreedom – immersing oneself in a pause, an intersubjective framework or by "living" – that ethical agency becomes possible.

B] The Re-Ordering of Risk and Gender

Numerous examples of women taking a pause and crafting their narratives of self and identity populate the medical anthropology/sociology record (see Becker 1999; Garro 2000; Gregg 2003, 2011; Hunt 2000; Kirmayer 2000; Kohler Riessman 2000; Pandolfi 2007; Rapp 2007; Saukko 2010; Thompson 2005, 2007; Throsby 2010). However, something quite specific took place when women spoke of their decisions to have their daughters or themselves vaccinated or not vaccinated against HPV. In an overarching sense, their ethical agency involved aspects of Thompson's "ontological choreography" (2005). Ontological choreography entails the "dynamic coordination" (Thompson 2005:8) of various aspects of self and in Thompson's ethnography it was primarily that of trying to become a mother within a fertility treatment-oriented medical encounter. In the case of patients, and more fleetingly students, ontological choreography was joined by the "biographical disruption" (Bury 1982:167) of being chronically ill. However, women's ethical agency in the pause also pointedly involved the re-ordering of gender and risk across all cohorts. For the women interviewed, risk and gender intersected in a "productive" (Zaloom 2004:365) manner. In other words, risk and gender were practiced when vaccine decision making occurred. HPV vaccine decision making provided the key that opened the door to understanding how gender and risk were appropriated (to answer research question two) to varying degrees of importance, and when health decisions were made (to answer research question three). These decisions were linked to the women's senses of self, and conceptualizations of risk and gender differed depending on where a woman was at in her lifecycle journey.

The women's narratives demonstrated that the concepts of risk and gender were adjustable ontological modes of doing – risk and gender moved in and out of focus depending on the context, but they were always present in some form, no matter how faintly. For mothers, risk was a theoretical construct: their daughters were just moving into their teenage years and the last thing they wanted to do was explore adolescent sexuality with them. HPV risk was a distant proposition. As a result, mothers focused much, much more – abundantly more – on gender and doing mothering. For students, HPV risk was intermittent because many of them had experienced transient HPV infections in the form of genital warts and the beginning of low-grade cervical dysplasia. Students were also outraged at the gendering of HPV and the vaccine and based their vaccination decisions on the type of gendered being they would like to be – one that was not put in a pre-determined, at-risk box. Students also worried about HPV vaccine risk as data concerning long-term side effects does not exist. As a result, students dealt with both risk and gender as a part of their doing; thus, they were doing gender politics and intermittent risk in equal measure. The risk students were doing was nothing like the risk patients were living with. Patients felt their risk was so encompassing that there was no means to escape it, but only strategies by which it could be contained. Because of the intensity of risk for patients, which they recounted in their diagnostic and treatment narratives, gender took a backseat. Patients were more focused on their HPV infection journey than their gendered senses of self. Narratives across all three cohorts indicate that in relation to women's sense of self, risk and gender are elastic concepts. When risk is distant, a primacy is placed on gender. When risk is coming into focus, both gender and risk are ontologically highlighted. And, when risk is ever present, risk takes centre stage with gender firmly placed in the shadows.

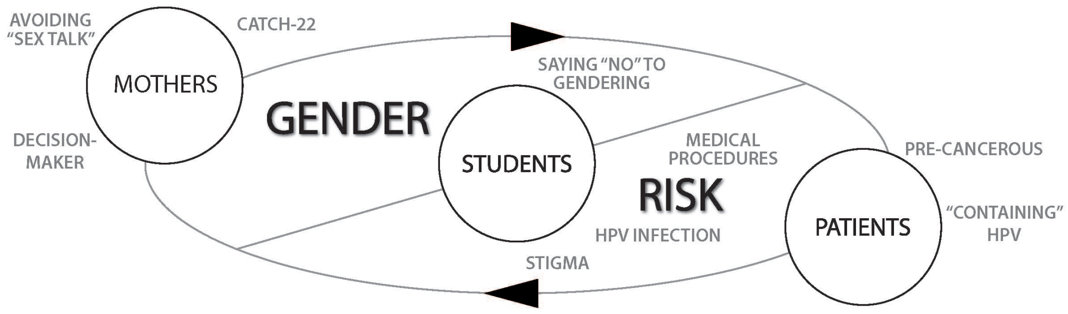

Figure 8 - Conceptual mapping of the re-ordering of risk and gender

However, before moving onto illuminating how women were entangled in their various forms of doing it is important to note that this doing did not reinforce the gendered at-risk subject formation of pharmaceutical and governmental discourses. Subject formations are power strategy configurations which attempt to order individuals or groups. These sales/governance strategies are trying to rein in their targets. Order is doubly signified here as the word denotes keeping subjects "in order" and prompting they follow governance orders. However, instead, this research project traced how women re-ordered *their* lives. As Douglas suggests with the concept of "disorder," re-ordering does exhibit "the potential for patterning" (2002[1966]:117). Re-ordering presents both a threat to order and the potential to enact power. Thus, while doing women are creatively re-appropriating/rejecting and hybridizing the gendered and risky HPV subject formation to productive affect. Butler describes this process of re-ordering:

> There is no making of oneself (*poiesis*) outside of a mode of subjectivation (*assujettissement*) and, hence, no self-making outside of the norms that orchestrate the possible forms that a subject may take. The practice of critique will thus expose the limits of the historical scheme of things, the epistemological and ontological horizon within which subjects come to be at all. To make oneself, then, in such a way that one exposes those limits is precisely to engage an aesthetics of the self that maintains a critical relation to existing norms. [2008:26-27]

Correspondingly, mothers ironically played with the concept of the good mother, students rejected mainstream concepts of gender and risk when saying “no” to the vaccine, and patients took a step back from the HPV treadmill by being vaccinated and setting their own parameters to contain HPV. Each woman did this on her own terms. Risk and gender were folded into the women’s senses of self in myriad ways across, between, and within each group of women.[61] What governance strategies have tried to “fix,” the women interviewed continually unfixed. With this in mind, the details of how each cohort was ensconced in its own modes of doing when engaged in HPV vaccine decision making is outlined below.

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[61] Rapp (1994) also found great variety within and across class groupings when she interviewed New York City women regarding amniocentesis. In my study, class is not used as a marker because most women interviewed were middle class.

C] Doing Mothering

As the narratives in chapter four reveal, mothers were highly invested in issues surrounding the HPV vaccine. As Carmen pointed out in our interview, HPV vaccine related messaging in pharmaceutical, governmental and mass media discourses emphasized that good mothers get their daughters vaccinated. Carmen's engagement reflects the continually negotiated process whereby mothers mediated between popularized notions of motherhood and enacted health strategies for their daughters they were comfortable with. These health strategies were also mothering strategies. Some may argue that the concepts of gender and mothering have been conflated, but doing mothering akin to Butler's performing or doing gender. Gender, says Butler, "is always a doing, though not a doing by a subject who might be said to preexist the deed" (2007[1990]:34). Doing gender is a continual process, not a discrete or concrete bodily motion, as women experienced in doing mothering. Thus, the analysis of HPV vaccine decision making among mothers traces the creative energy that "erupts" (Stewart 2000:245) when motherhood and mothering intersect. [62] Rich explains the motherhood/mothering dyad:

> I try to distinguish between two meanings of motherhood, one superimposed on the other: the *potential relationship* of any woman to her powers of reproduction and to children; and the *institution*, which aims at ensuring that that potential – and all women – shall remain under male control. This institution has been a keystone of the most diverse social and political systems. It has withheld over

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[62] This framing is similar to the contact between what Foucault describes as subject formation and the development of one's sense of self or ethics (Allen 2008) as discussed earlier in this chapter.

> one-half the human species from the decisions affecting their lives; it exonerates men from fatherhood in any authentic sense; it creates the dangerous schism between "private" and "public" life; it calcifies human choices and potentialities. . . . [F]or most of what we know as the "mainstream" of recorded history, motherhood as institution has ghettoized and degraded female potentialities. [1986(1976):13]

However, Rich's writings on the institutions of motherhood represent one half of her theoretical framework, with the other reflecting the everyday act of mothering. On the one hand, motherhood comprises the overarching strategies through which women are kept under the thumb of the dominant – and, predominantly patriarchal – order. Order is a key word here. One measure implemented to keep order was that of the "scientific mom" (Thurer 1994:225-6). The scientific mother was created in the first part of the 20th century when mothers were not considered to be innately qualified to "properly" rear their offspring. During this period, the medical establishment dispensed the requisite knowledge, procedures and guidelines for raising "healthy" children (Thurer 1994:225-6). The scientific mom is similar to mothers who are deemed to practice "intensive mothering" (Hays 1996:x) today. Resources harnessed in raising children as an intensive mother must also be "expert driven" (O'Reilly 2004a:8). On the other hand, mothering reflects the on-the-ground workings of being a mother – the re-ordering (and sometimes chaotic and dis-ordering) processes as described and defined by women. While motherhood is a subjugable form of power and, as Ginn argues, "is a form of social control exercised over women as they bear and raise children" (2004:32), mothering can function within spheres of agency, what Foucault calls being ethical and Butler deems ethical agency. Glenn emphasizes the agentive aspects of mothering:

> Mothering occurs within specific social contexts that vary in terms of material and cultural resources and constraints. How mothering is conceived, organized, and carried out is not simply determined by these conditions, however. Mothering is constructed through men's and women's actions within specific historical circumstances. Thus agency is central to an understanding of mothering as a social, rather than biological, construct. [1994:3]

When one is able to harness the everyday experiences of mothering on one's own terms, even for a fleeting moment – no matter how covert – the narrative of motherhood can be destabilized. This destabilization is evidenced in the narratives of the women interviewed, which harnessed the good mother discourse by enacting intensive mothering to productive effect. This is not, however, "authentic" mothering (O'Reilly 2004b:10), for this term inadvertently reifies mothering by bringing forth a singular mothering model against which mothers can be judged.

When motherhood and mothering intersected, mothers strategically accommodated, rejected and hybridized the institutional directives that were embedded in HPV vaccine public health, mass media and pharmaceutical messaging. Each woman drew upon her own unique set of experiences in determining the best vaccination measure for her daughter. Mothering was enacted through each woman's re-ordering of dominant HPV vaccine related discourses. This re-ordering allowed her to creatively re-formulate her identity, self-ascription and sense of self within existing power frameworks. Mothers creatively harnessed the good mother discourse and enacted intensive mothering to productive effect. Their re-ordering revealed the complicated and often ironic nature of mothering. As such, women initially appeared to echo dominant discourses surrounding motherhood, but a closer examination revealed they were re-fashioning the good mother precept in novel ways. Engaging in re-ordering while making a vaccine decision for a daughter provided the women interviewed with the opportunity to re-produce, re-create and re-enforce an aspect[63] of their own sense of self – their sense of being a mother.

The active negotiation of being a good mother resulted in vaccine mediation strategies that involved opting to get their daughter vaccinated, not vaccinated or delaying the decision. But, even within each decision category rationales varied as to why mothering strategies were carried out. For example, both Andrea and Heather decided to have their daughters vaccinated. Andrea's mothering strategy was slightly different than Heather's who had HPV-related complications in her early 20s and made her decision based on her HPV-related treatment experiences. Andrea provided a salient example of formulating health strategies linked to the very conceptualization of mothering, but instead of being contradictory, her decision making was steeped in irony. As Butler states, "[the fact] that my agency is riven with paradox does not mean it is impossible. It only means that paradox is the condition of its possibility" (2004:3). Andrea sought to shield her daughter from the downsides of being an intensive mother some day, all the while clearly enacting these canons herself. Andrea's vaccine decision may have mirrored dominant motherhood discourses, but she was, momentarily, attempting to

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[63] Being a mother is but one identity-ascription of the women interviewed. Women also identified as professional working individuals, sisters, aunts, partners, daughters and so forth, but during interviews their focus was on mothering strategies.

disrupt future hegemonic conceptualizations of motherhood so that her daughter would not have to do the same when she grew up. Thus, to form her own mothering strategies within the context of vaccine decision making and doing mothering was an act of hope. She was saying that just because she needed to navigate the maze of motherhood, didn't mean her daughter should have to negotiate these ideological frameworks. While Andrea's creative mothering strategies will not dismantle the overarching structures of motherhood, she began to loosen their grip. Her approach was a move to "undo restrictively normative conceptions of sexual and gendered life" (Butler 2004:1).

Neither Andrea nor Heather felt that the vaccine posed undue risk to their daughters. Andrea believed that the vaccine was similar in terms of risk to other childhood vaccines for meningitis or chickenpox. For Andrea, risks associated with contracting HPV, meningitis or chickenpox were far greater than any presented by related vaccines. While Heather too believed that all vaccines were potentially risky, her experience with HPV and related interventions was so strongly etched on her memory that the unpleasantness of her HPV experience outweighed any risk related to the HPV vaccine. Nor were Andrea or Heather willing to talk to their daughters about potential HPV infection risk because they were not comfortable talking to their daughters about adolescent sexuality; Carmen was the only mother to undertake this. The concept of risk – whether it was the risk of their daughters' experiencing potential long-term side effects associated with the vaccine or the risk of their daughters contracting HPV – was kept in the background by mothers like Andrea and Heather.

Other mothers interviewed, like Colleen, also invoked the good mother and intensive mothering narratives while engaging in vaccine decision making. However, these mothers decided against vaccination, and their re-crafting of these discourses took a different turn than that exhibited by Andrea and Heather. These mothers re-fashioned the popularized conceptualization of the good mother to stand for mothers who did extensive research regarding the effects of the HPV vaccine, did not want their daughters to be "test" subjects for a vaccine that had not been on the market for very long and who cared enough to say "no." These mothers, Colleen being one such, reinforced how pervasive the good mother and intensive mothering discourses are, regardless of a vaccination decision. Colleen believed that, as a society, we have become hyper aware of potential risks, to the point of paralysis. In response to, and in resistance to, living in what she conceived of as a "risk society" (Beck and Willms 2004), Colleen chose not to over think every potential risk. Thus, for Colleen, pharmaceuticals, which are manufactured by for-profit companies, brought about greater risk than the HPV virus itself and she actively resisted Gardasil® advertising that, in her own words, was set to make all mothers "afraid" for their daughters. Given this line of thinking, Colleen was being a good mother by protecting her daughter from the HPV vaccine, both in terms of potential vaccine side effects and "doing too much" to avoid hyped risk. Both the vaccine and too much stress were deemed to be "unnatural" and, thus, unhealthy. Colleen could, however, easily keep this vaccine risk at bay – she simply did not have her daughter vaccinated. For Colleen, the concept of risk was on her radar, but it was not a primary focus because she felt that she could control the risk through disavowal. For Andrea, Heather and Colleen, HPV infection risk was also a far off proposition – their daughters were not yet sexually active (at least to their knowledge). For those who opted for vaccination, long-term vaccine side effects were years away from materializing, if they developed at all. Thus, for both the mothers who had their daughters vaccinated and those who did not, HPV infection and HPV vaccine-related risk was considered a far off possibility despite their differing mothering strategies.

D] Doing Gender Politics and Intermittent Risk

As is outlined in chapter five, students were unhappy with the gendering of the vaccine and STIs, and the potential risk of the HPV vaccine. Student narratives provided a window into their uneasiness with how women have historically been are portrayed as sexualized beings, and the perceived lack of governmental involvement in setting the record straight. In their narratives students strongly critiqued the neoliberal individualization of the new public health whereby "social problems become utterly privatized and removed from public considerations" (Giroux 2010:4). Students discussed this theme by lobbying for de-gendering the vaccine, contesting the stigma associated with contracting an STI, and advocating for expanded sexual health education in schools and society as a whole, in order to temper the difficulties they had encountered in sexual health negotiation. They also expressed general uncertainty and mistrust in an age when medical "solutions" are delivered by for-profit entities. This mistrust and uncertainty was explored by student in conversations about living with the risk of intermittent HPV infections and their complex attempts to come to a vaccine decision they were comfortable with. As student decision making ranged from outright refusal to a delay in making a decision to changing one's mind about getting vaccinated, student narratives demonstrated that trust is a nuanced and layered concept when nested within situated risk negotiation.

1. De-Gendering and De-Individualization

Students were highly focused on doing gender, but were developing their sense of self or ethical identities by doing gender through resistance to being put in a box of the "feminine" (Moore 2010:96) by sales/governance strategies. Students were upset and angry with the gendering of the vaccine (and, hence, the virus) to the extent that 70 percent decided not to be vaccinated or delayed their decision.[64] The decision to forgo vaccination is a form of what Streefland et al. call "non-acceptance" (1999:1709) of the vaccination. In non-acceptance, individuals "question the need for vaccination" (Steefland et al. 1999:1710). When non-acceptance becomes widespread, collective resistance can emerge, but for students decision making occurred on an individual level. Historically, there have been many organized movements against vaccination, such as the 19th century grassroots campaign against smallpox vaccination in England, and

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[64] Whether or not this form of "negative agency" (Wardlow 2006) puts students at risk should be debated, but this is not the focus of the research. Public health policy makers and communicators should take note of how gendered framing affects vaccine decision making outcomes.

current day activism in the Netherlands against rubella and mumps inoculations. For students, however, there was "no organization, no active mobilization" (Steefland et al. 1999:1712).

Interestingly, though, in explaining their reasons for vaccine non-acceptance, students moved from the individualized sphere of vaccine decision making to seeking collective measures to address vaccine gendering and its social consequences. As Maya stated, the gendering of the vaccine and STIs made her feel "sick." Sylvana described this type of gendering as, "the wrong approach." Amber felt that current day gendering was the continuation of negative historical discourses vis-à-vis women that could be traced back to the 19th century. Maya's decision not to get the vaccine and Sylvana's decision to delay were both their way saying "no" to the gendering of the vaccine (and the virus) in governmental and pharmaceutical discourses.[65] Even Amber, who changed her mind in favour of being vaccinated after seeing a friend experience a protracted HPV infection, was conscious of the social implications that current, gendered HPV vaccine policy and pharmaceutical sales/governance strategies in Canada brought. Amber elaborated, "okay, so I have a problem, as I mentioned, with the vaccine even though I got it. I fundamentally have a problem with it because the way it's being marketed towards girls, stigmatizes girl's and women's sexualities as being a part of the problem." As

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[65] It is important to note that students did not speak about being targeted because of their age. Discourses surrounding youth and risk are rife in public health programming (see Brown et al. 2013; Spencer 2013; Thing and Ottesen 2013) and society in general (Giroux 2010), but students ranged in age from 20 to 28 and they did not consider themselves to be "youth."

Gregg notes, “STDs are . . . particularly stigmatizing for women, for whom cultural ideals of premarital virginity, marital monogamy, and respectability clash with the reality of sexually transmitted infections” (2011:77).

Sylvana and Maya resisted the subject formation of the risky, HPV-related girl/woman by saying “no” to the vaccine, but at the same time they were acutely aware of gender imbalances in sexual health negotiation. As such, their vaccine negotiation was rife with similar “paradox” (Butler 2004:3) and complexity that mothers experienced. Students spoke in great detail about negotiating sexual health as a challenging endeavor (see Roche et al. 2005; Richens et al. 2003; Shoveller et al. 2010; Thomas 2005). Sexual health gender imbalances brought risk into their daily lives. In practice, as Sylvana explained, women experience vulnerability, just as she did when she contracted genital warts from her boyfriend when she thought they were in a monogamous sexual relationship. Sylvana opined that in an effort to avoid “all sexual transmittable diseases, the first step to preventing them is communication between partners and equal involvement of both partners in awareness of their risks and just check ups and things like that, like knowing your status related to various diseases.” While this would be the ideal scenario, Sylvana herself experienced a breakdown in such communication when her partner was unfaithful and she was left, as she said, “exposed.”

Maya also spoke about the vulnerability young women experience in sexual encounters. She elaborated:

> But then there's also the layer of young girls not being empowered to make these decisions as well. So, that has nothing to do with education. Like you may right know that having unsafe sex, unprotected sex is dangerous but that you don't necessarily have the power to make that choice in the situation. And so that adds another dimension to it.

Like Maya, students did not always feel they had the power to press for the use of barrier contraceptives while engaging in sexual practices. They might indeed have known that not using such measures could lead to STIs, but they did not always feel they could advocate for their own health concerns in such situations without alienating a male partner. This, coupled with the fact that partners were not always faithful, made students feel vulnerable. While Maya's and Sylvana's decisions not to be vaccinated can be placed within the frame of doing gender through resistance, Amber's "yes" decision can also be viewed as being a form of quiet protest. Amber may not have refused vaccination, but she deployed vaccination as a tool to help strengthen her position in future sexual health negotiation. Amber revealed, "I guess my own concern about my sexual health outweighed any potential problems that might come with it. And, so, which is why I decided to get it." Thus, students demonstrated that resistance was as intricate as the paradoxes exhibited by mothers and could not be measured by vaccine decision outcomes alone.

Students, overall, urged for a more open climate about sex, sexual relations and STIs. They reasoned that if more people talked openly about sex, sexual health negotiation would be more balanced; if such a climate existed both men and women would be aware of STI risk and take measures to protect themselves. They posited that delivering an STI-related vaccine – the HPV vaccine – in school settings across the province and country while not leveraging this program to provide accompanying sexual health education was a missed opportunity. Not only did students wish for sexual education curriculum to include HPV as a topic, they were convinced that if sexual education was covered more frequently and in more depth in both primary and secondary schools,[66] not only would young women be aided in negotiating their sexual health, it would help lift the STI-related "stigma" (Goffman 1963). They argued that the more sex, sexual relations and STIs were talked about, the more individuals would realize how commonplace they were. This would alleviate the compulsion to shroud such experiences in silence for fear of being judged. As Maya insisted, instead of being considered a big or traumatic event, "people should think of HPV as part of a normal, healthy sexuality because it can't necessarily be prevented, so if you are going to have sex, you are going to end up getting HPV, probably, at some point." Maya did not put the onus solely on the educational system, she stressed that society as a whole, must also start to "talk about sex."

By wanting to bring sex and sexual relations into everyday conversation, students were not only aiming to ease the stigma – they were trying to resist it. This was an effort in re-ordering daily discourse. Through this suggested re-ordering, they resisted the social exclusion that resulted from others knowing they had contracted an STI and being

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[66] Lear (1995) also found that young adults reported that the sex education they received before university was "woefully inadequate" (1317).

depicted as “dirty” or “deviant” women. Although writing about disability, Das describes the effects of social exclusion:

> The entire discourse of anxiety that surrounds the stigma of deformed bodies thus is about reduction of sociality, exclusion from moral community as well as subjective feelings of guilt and shame. Being cast out of the social community coupled with a diminished sense of worth reduces the capability of the afflicted person to seek help even when this is in objective terms, easily available. [2001:5]

Student resistance to the gendering of the vaccine and the virus, vulnerability in sexual health negotiation, and the stigma associated with STIs were all factors integral to their developing sense of self as young women. Their telos involved rejecting being painted as “dirty” and “sexualized” women, all the while being acutely concerned about the uneven power relations present in sexual health negotiation with male partners. This was a complex form of risk negotiation because on the one hand they were out rightly refusing to be identified as risky sexual beings, but on the other hand, they were trying to find ways to mitigate their risk as sexually active women who had contracted STIs. Their prescription for dealing with stigma was increased sexual health education, both in schools and in society in general through public health measures. Students attempted to adjust the neo-liberal devolution of public health services, which has been rampant under the auspices of the new public health paradigm (Lupton and Petersen 1996), by urging for greater sexual health education in schools. As such, students were trying to shift the onus for public health education from the individual back onto the state.[67] Thus, their negotiating risk was cast as a re-ordering of existing power structures, but not in a way that dissolved the institution currently perpetuating the subject formation of the HPV-oriented risky young woman. As for mothers, for students there was "no self-making outside of the norms that orchestrate the possible forms that a subject may take" (Butler 2008:26-27). This speaks to student recognition that risk is a social product – if it can be constructed as an individual and gendered problem through sales/governance strategies, these premises can also be de-constructed through state provided educational programming.

2. Risk, Uncertainty and Trust

Students were also doing a form of risk – they were living with intermittent HPV infections. Their risk came and went for several reasons. First, robust immune systems (at their relatively young ages) typically clear HPV infections that cause cervical dysplasia on their own. Secondly, medical treatments for genital warts ensured that these types of infections did not last long and finally, genital warts are the result of low-risk HPV strains, which do not lead to cancer. As a result, the student's version of living

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[67] As students wished for the state to re-engage with sexual health education they were not engaging in Beck's notion of subpolitics when opting out of being vaccine consumers. As such, students were not taking part in the "re-politicization of areas outside the iron cage of bureaucratic politics" (Holzer and Sorensen 2003:80), but were seeking to reinsert themselves into governmental apparatuses.

with risk focused on the brief HPV infections that they encountered. Students such as Sylvana and Maya spoke at length of contracting genital warts, all cases of which cleared following medical attention. These cases did not present long-term physical effects, save for the emotional toll that contracting an STI brought. However, these intermittent experiences caused students to enact their own forms of telos in order to mitigate future HPV infection risk. For example, Maya managed her sexual health by engaging in sex only with barrier protection unless she and her partner had received negative STI tests. She used condoms when necessary and had a Pap test at her yearly physical with her GP. These active strategies helped Maya manage sexual health negotiation and to keep an eye out for dysplasia. Maya refused the HPV vaccine because of its associated gendering, but she was also concerned about potential risks because it was a relatively new vaccine without a long-term research profile. Maya stated, “so I don’t know how anybody can expose themselves to a drug that they don’t know how it’s going to affect them in the long term. I think that’s kind of crazy, so I wouldn’t advocate for anybody taking the vaccine.”

Risk was clearly at the forefront of Maya’s mind – not only the risk of contracting an STI, but also whether or not there was a risk associated with the vaccine. As Giddens notes, the increase of information circulating in what he deems to be the current phase of modernity often leads, ironically, to what he calls “non-knowledge” (1991:217). Thus, the “question of *deciding in a context of uncertainty* arises in a radical way” (Giddens 1991:217, emphasis in original). Individuals are unable to assess long-term outcomes to such incidents as environmental spills, genetically modified foods and emerging medical technologies, like vaccines. This creates a climate of uncertainty in which it is difficult to make health-related decisions. When there is uncertainty, "[e]verything falls under an imperative of avoidance" for no one wants to be the unlucky one who experiences complications, "gets 'sick' and many even die as a result" (Giddens 1991:217). As an example, Sylvana, who also had experienced genital warts, could not bring herself to decide whether or not to be vaccinated. Sylvana, like Maya, was concerned about the potential risk of the vaccine. Sylvana did not feel that vaccines were generally "well researched" and she was skeptical because the HPV vaccine only protects against four strains, when over a hundred strains have been documented. Students had little trust in the vaccine.

In a time of uncertainty, trust is a concept that is difficult to navigate. According to Giddens:

> Trust . . . is basic to a "protective cocoon" which stands guard over the self in its dealings with everyday reality. It "brackets out" potential occurrences which, were the individual seriously to contemplate them, would produce a paralysis of will, or feelings of engulfment. In its more specific guise, trust is a medium of interaction with the abstract systems which both empty day-to-day life of its traditional content and set up globalizing influences. Trust here generates that "leap into faith" which practical engagement demands. [1991:3]

In order to trust in late modernity, Giddens theorizes that an individual must have a sense of psychological "security" (1991:18). Continually emerging risks work to destabilize a sense of security. The "protective cocoon" that is required in order to go out into the world on a daily basis and partake in everyday risk inducing activities, such as driving and crossing the street, can be harder and harder to keep on doing in times of uncertainty (Giddens 1991:40). The "bracketing-out of possible events or issues which could, in certain circumstances, be cause for alarm" is no longer necessarily possible (Giddens 1991:127). In short, if an individual's sense of "basic trust is fragile . . . even contemplating a small risk, particularly in relation to a highly cherished aim, may prove intolerable" (Giddens 1991:182).

Correspondingly, Sylvana had difficulty trusting pharmaceutical companies. She was weary of, as she said, "putting stuff in my body that I don't know exactly what it is and what is does. What it essentially is, I get it, a cash grab by a pharma company." It is not uncommon for individuals to mistrust medical products that have been developed by for-profit entities because positive notions of health and health care are more often associated with non-profit spheres (Gross and Shuval 2008:553). However, to feel at risk after having experienced multiple HPV infections and then having been made to feel further at risk by a medical solution, such as the vaccine, left Sylvana at a loss. This translated into a delayed decision regarding the vaccine; she put off the decision until further longer-term research could be done, at which time she felt she would be able to trust the vaccine. Sylvana did not make her decision to delay without reservations, though. She stated, "it's a hard kind of choice to make. But at the same time, how stupid would you feel if you ended up getting cervical cancer and had decided not to get vaccinated. I have mixed feelings so it was why I've held off on getting the vaccination." The notion of trust did, however, take on various gradations in relation to vaccine decision making for students: Maya exhibited patent rejection of the vaccine, Sylvana showed uncertainty which resulted in a delay in decision making, and Amber demonstrated enough trust to undergo vaccination, even though she did not agree with the sales/governance strategies used to promote the vaccine. Student experiences demonstrate that trust is a nuanced and layered concept. And, as is exemplified by Amber's change of heart (her initial decision to forgo vaccination was reversed when a close friend experienced HPV-related complications), trust can also be dynamic and changing. As Walls Dr. et al. (2010) explain, "critical trust lies on a continuum between outright skepticism (rejection) and uncritical emotional acceptance" (147).

Student engagement with situated risk – whether it was the risk of intermittent HPV infections or their negotiations of uncertainty and trust vis-à-vis the vaccine – foreshadowed the intimate interaction patients had with risk. However, patients were living with risk associated with pre-cancer diagnoses. This type of situated risk was far more intense than the risk experienced by students and provided a milieu whereby the vaccine was but one component of their HPV infection experiences. As such, HPV-related diagnoses and procedures took centre stage.

E] Doing Risk

What is it like to be between being well and unwell? How did patients at the clinic deal with being labeled pre-cancerous? The answer is that they lived with risk on a daily basis. Risk operated as the central mechanism through which patients "organize[d] the[ir] social world" (Giddens 1991:3). This risk included not only being attributed as an at-risk woman by the medical establishment, but actively doing risk. Doing risk refers to how the "biographical disruption" (Bury 1982) associated with a chronic illness contributed to how women patients developed their sense of self – ultimately, their ethical being – at that particular point in time in their lives. As Bury explains "Illness, especially chronic illness is precisely that kind of experience where the structures of everyday life and the focus of knowledge which underpin it are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others" (1982:169).

As a result, a person's sense of identity or self is re-ordered in such a circumstance. And in this case patients had to calculate and calibrate how they would respond to their shifting environment and how they would engage in "mobili[zing] resources, in facing an altered situation" (Bury 1982:169). As per Douglas, "organizing requires classifying, and that classification is at the basis of human coordination" (2002[1966]:xvii). Patients used the need to re-order their lives in the face of protracted HPV infections and the requisite medical interventions to make sense of what was happening to them. As the mothers and students experienced, patient re-ordering took place within existing societal frameworks. The making of one's ethical self always takes place within the confines of existing norms. Just as mothers re-appropriated what it meant to be a good mother from dominant discourses, patients re-appropriated biomedical definitions of risk by re-fashioning meanings of risk to reflect *their* cervical dysplasia experiences. Their lived experience with risk was different than how the medical establishment looked at risk. Rapp refers to this interchange as the "traffic between biomedical and familial understandings" (2000:185). This traffic is essentially the same creative process of self-making that occurs when motherhood and mothering come together. As with mothers and students, patients were also faced with navigating external subject formation, all the while developing one's sense of self or ethics.

Patients exhibited changing conceptualizations of cervical cancer risk that differed from their attending general practitioners, who had first diagnosed abnormal cervical cells before they were referred to a gynecological specialist. In Zoe's experience, her GP spoke about cervical cancer as stemming from multiple sources (cf. Weiss 1997). While patients viewed cancer in general as such, they had differing views of cervical cancer. For patients, cervical cancer etiology was not multi-causal, but reflective of a direct line of cause and effect: the sexually transmitted HPV virus caused cervical cancer. However, even with the direct line that they could draw, patients felt helpless in preventing HPV infection. This linear disease pathway was complicated by the knowledge there was little one could do to prevent HPV transmission if engaged in sexual relations. Using barrier contraceptives was not necessarily going to block HPV transfer, as it is based on skin-to-skin contact and not fluid exchange (Braun and Phoun 2010:50). Therefore, there was no way to protect oneself from HPV unless one abstained from all forms of sexual contact. Nor can one be cured of HPV infection for the virus can lie dormant for decades. The old rules of health risk management, which promote a conception of the self that is motivated to self-regulate – a person who actively manages their health through proper diet and exercise and who stays away from perceived health risks (Nettleton 1997) –were no longer relevant.

In the case of STIs, the old rules of health management risk would have emphasized practicing safe sex – but these rules cannot be applied to HPV. New modes of "self-care" (Foucault 1988) are required when dealing with HPV, but patients were somewhat at a loss as to what they should entail and how they should be carried out. They were at a "crossroads" for living with HPV-related risk is "uncharted territory" (Giddens 1991:142). As Giddens explains, "the individual has to confront novel hazards as a necessary part of breaking away from established patterns of behavior – including the risk that things could possibly get worse than they were before" (1991:78). As a result, patients looked to contain, instead of prevent HPV, which is a distinct, emerging health strategy. Jennifer, who had experienced abnormal Pap test results for the last ten years and had undergone biopsies, colposcopies and LEEP procedures spoke about bolstering her immune system by eating well and exercising in order to not "run into anything big," meaning having abnormal cells turn into cancer. However, Jennifer was the only patient who spoke about doing things on her own through self-regulation to prevent her abnormal cells from turning into cancer. The remaining patients, instead, turned to Pap tests and other HPV-related procedures, such as colposcopies, to limit the eventual development of HPV-related abnormal cells into cervical cancer.

Patient routines of medical appointments and procedures became their form of self-care – a new telos to contain HPV-related cervical dysplasia. This telos was devised to deal with their protracted living with risk status. As Bury (1982) describes, chronic illness involves setting new routines – a "new normal" so to speak. The long term Pap test surveillance, which accompanies medical treatment, caused a great deal of anxiety and emotional anguish among patients. Experiencing anxiety is a common by-product of being classified as "at-risk." When deemed "at-risk," it is not possible to maintain the "protective cocoon" (Giddens 1991:181) one needs to navigate the risk of day-to-day life. As was also seen with students, patients no longer were able to suspend the notion of risk after HPV-related diagnoses. Instead, medical encounters became riddled with anxiety. Once diagnosed with cervical dysplasia that did not clear on its own, patients stepped onto an HPV treadmill and had to stay on it to contain HPV. Rebecca was a prime example of this for she had been experiencing abnormal Pap test results, biopsies and finally a LEEP for the last ten years. She described her dysplasia as "constantly going on" and lived in fear that the next test would be, as she called it, "really abnormal this time". By "really abnormal" she was referring to cancer. Jennifer described her colposcopy experience as involving “fear” and “pain.” Kathryn also had an unpleasant colposcopy experience. She spoke about her doctor describing it as a simple procedure involving little pain, and comparing it to a Pap test (this happened to several patients interviewed). Her experience of a colposcopy, however, could not have been more different than that of having a Pap test. Kathryn spoke about bleeding for an entire week afterwards and having an overall “icky feeling – like I needed a shower.” Kathryn had the urge to “cleanse” herself after a colposcopy. This signifies a need to purge oneself of an anxiety-ridden event. Additionally, it may also be a way to rid oneself of the virus and its accompanying abnormal cells. Having cervical dysplasia put Kathryn in the indeterminate state of pre-cancer – between healthy and unhealthy. The virus and the accompanying medical treatment caused “disorder” in Kathryn’s life and “eliminating it [was] not a negative movement, but a positive effort to organize the environment” (Douglas 2002[1966]:2).

Wanting to re-order their experiences, wanting to alter their pre-cancerous state was, no doubt, accelerated by the negative judgment patients received from physicians. Jennifer spoke the most passionately in this regard and described how her initial diagnosis of dysplasia was “disappointing,” “upsetting” and made her feel “unclean” and like a “pariah.” She went as far as to state, “I will remember it forever. I felt pretty bad.” It is important to note that Jennifer used the word “unclean” in her response to physician judgment. Like Kathryn’s needing a “shower,” she was also, unconsciously, referring to the need to purge or clean away – hence, to order or re-order disorder. To choose words like “unclean” may appear to parrot dominant discourses about STIs – which focus on “dirty” and “infected” individuals, but Jennifer was actually managing her biographical disruption the best way she can. And, as occurred with the students, having stigma leveled against them also affected how patients orchestrated this re-ordering – they were reminded by others that they were not the same as they once had been, nor the same as those who did not have an STI. In doing so, the medical establishment created and reinforced the classification of the “healthy” self versus the “unhealthy other” (Crawford 1994). Their choice of words and attitudes towards patients left the patients no choice but to reassert their morality and self-worth.[68]

As a result of not being able to prevent HPV infection, patients expressed a clear sense of inevitability about developing cervical cancer. Kathryn and Rebecca felt that there was a possibility of developing cervical cancer and Jennifer was more direct in stating that she felt it would be “naïve” to think that would not happen. This “fatalism” (Drew and Schoenberg 2011) is common among cancer patients and those experiencing chronic illness (Bury 1982). This sense of fatalism is also germane to those who feel at constant risk. Giddens explains his perspective on risk and fatalism:

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[68] When speaking about my research with a colleague, she described my interviews as a Foucaultian confessional. While the comparison is understandable as patients appeared to be undergoing a “therapeutic exercise” (Lupton 2003:31) during interviews, I would argue that some may perceive me as having a degree of power as an academic researcher working in a hospital setting, but patients appeared to want to talk to me precisely because I was not a physician. Perhaps, as well, the fact that they were not required to have contact with me beyond the interview, as they were with their physicians, also prompted them to be so open. They knew there would be no long term repercussions of speaking candidly with me.

> Fatalism, as I understand it here, differs from stoicism, an attitude of strength in the face of life's trials and tribulations. A fatalistic outlook is one of resigned acceptance that events should be allowed to take their course. It is an outlook nourished by the main orientations of modernity, although it stands in opposition to them. [1991:112]

As Giddens posits, taking on the sense of fatalism seems ironic considering that the period of late modernity was supposed to usher in progress and greater control by humans over nature. However, instead of feeling any measure of control, patients were resigned to "pragmatic acceptance" (Giddens 1991:131) of HPV-related risk as they were forced to deal with their pre-cancerous status one day – or procedure – at a time.

Opting for HPV vaccination was another measure of self-care in the telos of containing HPV, but it was not deemed to provide any measure of certainty. Jennifer was the most optimistic of the patients in terms of the vaccine, but she waited before proceeding due to the cost. After some investigation, she confirmed her insurer covered the shot, although they did not "make it easy," as she said, to find this out. Jennifer's overarching motivation to get vaccinated was to avoid more time on the HPV treadmill. Jennifer explained she "needed to take every step possible to never have to deal with any abnormal cells possible." Rebecca decided to be vaccinated in order to "take advantage of what all is available today," but did not feel that the vaccine would work for her, thinking it was "too late." Kathryn was happy to find out she was eligible for the vaccine when she had been told repeatedly by her GP that she was not. Kathryn was worried about possible long-term vaccine effects, but was reassured, through her own research and in consultation with her gynecologist, that she would be fine. Kathryn's decision to be vaccinated was motivated by the fact that she would do anything possible to avoid having to undergo another colposcopy, biopsy or LEEP. Her decision was also an effort to stave off "the next phase," meaning cancer. Zoe noted she was not sure if the vaccine would help her, but she figured she didn't have anything to lose by getting vaccinated.

During the pause of the interview, Zoe, Jennifer, Kathryn and Rebecca suspended their pre-cancerous status – it was as though they temporarily escaped the liminality of pre-cancer and could put aside the feelings of anxiety associated with being in an indeterminate station in life. The women were not passive recipients of medical and political technologies when they engaged in HPV vaccination. For patients, vaccination was a "transformative" act (Polzer 2010:71) through which they could recharge and continue with their self-care before their diagnoses and treatment protocol shifted again in response to the mercurial and non-linear qualities of HPV infections. Patients knew that the HPV vaccine would not cure them, and were skeptical that it would prevent future infection, but they were transformed through vaccination nonetheless.

Before closing this section of this chapter, it is important to reflect upon what patients were not saying. What are the "unsaids" (Foucault 1989[1969]:124)? Patients were not broaching the subject of gender, their gender, or how gender was projected in HPV-related pharmaceutical and governmental policy discourses. In the case of patients, risk trumped gender. Living with risk while on the HPV-related procedural treadmill was their focus. Gender was not a central component of patients' senses of self as it was with mothers, nor was it a significant factor as demonstrated by students. In essence, gender was re-ordered almost right out of the picture. Central to patients' sense of self was how to live with, manage and do pre-cancer risk for protracted periods of time. They were more concerned with containing HPV in the hope of staving off cancer than anything else. Their own type of ethical agency depended on re-ordering their lives in response to biographical disruptions by pulling together their internal resources and managing the medical establishment, which often had views of their "risk" that differed from they did. Patients had to, ultimately, deal with the anxiety their indeterminate health status brought. This was why the pause vaccination brought was such an important event through which patients could stop, take a deep breath and prepare to move forward, no matter what their on-going diagnoses would be.

Conclusion: Ontological Decision Making

While re-ordering risk and gender, women were making sense of and deriving meaning from their everyday lives. Throughout the processes of re-ordering, women were "doing." Mothers were doing mothering, students were doing gender politics and intermittent risk and patients were living with risk. In carrying out each aspect of "doing", women wove nets of experiences, which when assembled helped form their ethical being or sense of self. For example, mothers were deeply entrenched in performing their versions of being a good mother. This encompassed navigating the opposing spheres of motherhood and mothering and finding a comfortable space for themselves somewhere in between these two ideological and pragmatic constructs. This navigation was made possible by enacting numerous forms of intensive mothering. In intensive mothering, mothers “do” plenty. They researched vaccines, consulted widely about their daughters’ health and actively participated in mothering so that their daughters would not have to, ironically, be so “hands-on” when they were mothers themselves. For the mothers interviewed, mothering was an intrinsic part of their situated gender identity as adult women. This sense of identity was so strong that they refused to discuss adolescent sexuality as this would mean broaching the issue of their daughters growing up, and would mark the beginning of a period in which their daughters would shift into womanhood themselves. Intensive mothering cannot be practiced with adult children and the women interviewed were not yet ready to contemplate a more “hands off” approach to mothering.

Students were also actively fashioning their ethical beings or senses of self when navigating HPV vaccine decision making. As women who were emerging into full-fledged womanhood, students were attempting to mediate gendered stereotypes associated with STIs by advocating for the de-gendering of the vaccine. They were also strongly critiquing neo-liberal public health measures, which placed the onus for sexual health education and negotiation on the individual. Students wished to introduce HPV-related and STI focused education campaigns into the school system and society as a whole. This was in an effort to redistribute the blame associated with contracting an

STI. They reasoned if more information circulated regarding HPV, the virus would no longer be considered a woman's issue. These themes were central to how they identified as a woman – they wanted to be considered on equal footing with men and declined a vaccine, which they associated with gender asymmetry. However, student identity making was fraught with tension. While it was clear what type of women they wished to be, actually mediating HPV infection risk and the potential risks of the vaccine, proved to be rife with uncertainty. Students had begun to experience intermittent HPV infections, but felt the vaccine was too "new" to be trusted. Opposition to "big pharma" and uncertainty surrounding vaccine side effects caused students anxiety. They felt vulnerable to vaccine risks, just as exposed as they felt while negotiating their own sexual health. Thus, for students, the concept of situated risk was fraught with continual negotiation. Being a strong, certain woman in the face of mistrust and uncertainty was a difficult and tenuous ideal to actualize.

While students had opened up the "protective cocoon" Giddens (1991:3) spoke about when mediating their mistrust and uncertainty associated with sexual health and vaccine negotiation risk, patients had completely emerged from its casing. Patients' ethical agency and sense of self had experienced biographical disruption. Being designated a pre-cancerous individual meant their lives had to be completely re-ordered. The old health strategies they had followed no longer applied. New strategies to contain, rather than prevent HPV had to be assembled. They experienced friction with the medical establishment when they were stigmatized by physicians for having contracted STIs and had to continually re-assert themselves as moral individuals in the face of this discrimination. They did, nonetheless, reach “pragmatic acceptance” (Giddens 1991:131) of their status as pre-cancerous. This involved undergoing their medical procedures and shifting diagnoses day-by-day, but it also meant that they felt cancer was a realistic outcome for them. This fatalism, coupled with the anxiety associated from a litany of medical procedures, made patients feel as though they might never get off their HPV infection “treadmills.” For patients, situated risk was not a concept, but a tangible part of their everyday lives. It required that they shift their approaches to life as each diagnosis and treatment came their way. While they recognized that the vaccination might not bring a benefit considering their medical histories, they accepted the vaccine and the moment of respite it provided.

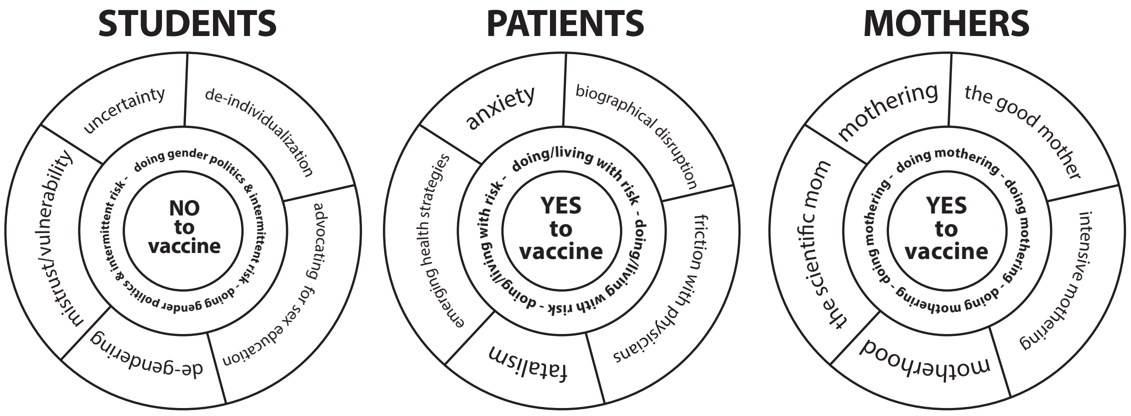

Figure 9 – Conceptual mapping of ontological decision making

As women’s “doing” and identity making was not teleological and rested within a web of experiences, so too was their vaccine decision making. The knowledge accumulated through situated risk and gender experiences, or “experience-based knowledge” (Zinn 2008:443), was then layered to form vaccination decisions. Positing that women took an ontological approach to vaccine decision making is a marked departure from existing literature surrounding risk decision making. Current risk decision making research posits that decision making is the result of linear, cost-benefit analyses (Austin et al. 2013; Jacobson et al. 2007; Poland et al. 2009; Poland and Jacobson 2001). For example, Crighton et al. (2013) argue that such approaches involve “two cognitive mediating processes: the threat appraisal process evaluates the potential benefits of action as well as the availability of resources (financial or other) to do so” (298). This type of linear, cost-benefit analysis also positions decision making as a “rational” and individual act. And when individuals do not follow risk prevention directives, they are often cast as ill informed or not being able to grasp the complexity of the risk issue at hand (Lupton 1999a:2). This approach does not recognize that decision making is “more a process than an isolated action” (Hobson-West 2010:280). In short, it misses the “situatedness” of risk (and gender for that matter). Ontological decision making is an inherently social and cultural process, which is embedded in women’s experiences of “mobilizing meanings” (McClure 1991:365) surrounding their efforts to be good mothers, strong young women merging into adulthood and pre-cancerous patients seeking a “pause” amidst the anxiety of seemingly never-ending cycles of medical procedures.

CHAPTER EIGHT - Conclusion: Contributions and Considerations for Moving Forward

A] Research and Analysis Summary

This research project has been an endeavor in answering three overarching questions: (1) How did the HPV vaccine become gendered within the Canadian policy landscape, which then lead to gendered public health programming? (2) How do women appropriate, hybridize or refute the notions of "gender" and "risk" that are deployed in association with the vaccine? (3) How were their experiences with risk and gender folded into their vaccine decision making? In an attempt to answer these questions, fieldwork took on two phases. In the first phase, the creation and circulation of the concepts of "gender" and "risk" that were deployed in pharmaceutical and policy discourses vis-à-vis the HPV vaccine were tracked through archival research comprising Gardasil® advertising campaigns, popular media accounts, parliamentary debates, federal and provincial press releases, accounts of lobbying before the federal Finance Committee and federal regulatory decisions regarding the vaccine. As policy documents indicate, the federal government developed HPV vaccine policy within a GBA frame, which followed the parameters of Merck Frosst's gender-based marketing. Such gender "ideals" rest upon the overarching notion that women are a "feminine" grouping – a homogenous and static “whole” that is inherently at risk for ill health. Merck Frosst was the first to deploy these governance techniques as a selling mechanism for the vaccine, but if these conceptualizations were not in the ether, they would not have been picked up again in policy making. The policy sphere, as with all other facets of daily life, is rife with the circulating, yet static, cultural “ideals” of gender and risk.

The archival contextualization provided the requisite background to conduct the second phase of research, the tracing of how the concepts of “risk” and “gender” were mediated by three different groups of women: mothers negotiating the vaccine for their daughters in a school-based immunization program; university students who were targets of HPV vaccine promotion in campus health clinics; and patients who simultaneously attended hospital-based HPV vaccine and colposcopy clinics. It was not particularly surprising to discover that a multinational pharmaceutical company lead governmental policy development, but what was *really* at the centre of the research was the quest to understand how women were negotiating, within everyday contexts, these conceptualizations of “gender” and “risk.” How were these concepts folded into their vaccine decision making? Perhaps risk was emphasized more than gender, or was it the other way around? In answering these questions, the vicissitudes of power were examined – how power was deployed and how it was processed.

In order to analyze the data gathered, Foucault's early and late theory (1987, 1989[1969], 1990[1978], 1991, 1997, 1999) was utilized. Additionally, Douglas's (1992, 2002[1966]) work on risk and the work of those who follow the governmentality school of risk (Castel 1991; Gordon 1991; Lupton 1994, 1995, 1999a, 1999b, 2003; Lupton and Petersen 1996; Nettleton 1997; Petersen 1997; Rose 2007; Rothstein 2006 and Turner 1997) were brought into the theoretical fold. Governmentality approaches have been critiqued for their predetermined nature (Sawicki 1991:98); however once I examined the continuum of this work, tightly woven governance strategies began to loosen, and one could even say, began to unravel. By examining Foucault's work on its continuum, I was able to acknowledge the construction of subjects within the frameworks of power relations as well as the possibility that such subjects could level their own "critique" while enmeshed in power networks (Allen 2008:21). Women's narratives provided an intersubjective space where subject formation and realizations/actualizations of the self intersected and it was in this space that health negotiation and decision making occurred. In the intersubjective space women worked towards becoming "ethical" beings by creating their own "telos" or sets of codes for maneuvering daily life (Foucault 1997:265). Scripting one's telos is a limited act of power and this reflects the women's ability to be "self-constituting" (Allen 2008:2).

The use of early and late Foucault theory, along with writings by Allen (2008), Butler (2008), Nettleton (1997), Lupton (1997b) and Zaloom (2004) allowed for the analysis of situated risk (Boholm 2003) and gender. This is where this research project makes its greatest contribution to existing social science literature related to risk. Research in social science fields focusing on risk, generally zeroes in on either grand theory (see Beck 2004; Castel 1991; Dean 1999; Giddens 1991; Gordon 1991; Ewald 1991; Fox 1997; Petersen 1997; Rothstein 2006) *or* individual accounts (see Bond et al. 2012; Brown et al. 2013; Crighton et al. 2013; Gross and Shuval 2008; Lear 1995; Russell and Kelly 2011; Spencer 2013; Thing and Ottesen 2013; Tuinstra et al. 1998; Walls Dr et al. 2010; Zinn 2008). Concentrating solely on grand theory leaves out the important human element of risk, and exclusively researching individual experiences, unintentionally, reproduces sales/governance strategies. However, as important as research focusing on situated risk is, it is usually not extended to issues relating to gender in a critical fashion (Lupton 1999a). Moore (2010) also notes that if gender is addressed in situated risk research, gender is treated with such limited theorization that findings usually reinforce gender norms. However, this research project addresses this void in the academic record by treating both the concepts of “risk’ and “gender” with critical care, all the while producing ethnographic accounts of women’s experiences negotiating risk *and* gender.

As eighteen months of fieldwork delving into situated risk and gender revealed, something quite specific occurred when women recounted deciding whether or not to have their daughters or themselves vaccinated against HPV. Their ethical agency involved aspects of ontological choreography. In the case of patients and more fleetingly students, ontological choreography was joined by the biographical disruption of being chronically ill. When ontological choreography and biographical disruption intersected, women consciously engaged in re-ordering. Thus, the concepts of risk and gender were movable ontological modes – risk and gender shifted in and out of focus depending upon the context, but they were always present in some form, no matter how faintly. For mothers, risk was a theoretical construct; their daughters were just moving into the teenage years and they did not wish to explore adolescent sexuality with them. HPV risk was a distant proposition. As a result, mothers focused on gender and doing mothering. For students, HPV risk was intermittent for many had experienced transient HPV infections in the form of genital warts and the beginning of low-grade cervical dysplasia and, moreover, were worried about potential vaccine side effects. Students were also angry with the gendering of HPV and the vaccine and based their vaccination decisions on the type of gendered being they would like to be – one that was not put in a pre-determined, at-risk box. Students were, therefore, dealing both with risk and gender simultaneously. The risk students experienced, however, was nothing like the risk patients lived with. Patients thought their risk was so overwhelming that there was no means whereby they could escape it. All they could do was develop health strategies to contain it. Due to the intensity of risk for patients, which they recounted in their diagnostic and treatment narratives, gender took a backseat.

Narratives across all three cohorts indicate that in relation to women's senses of self, risk and gender were elastic concepts. When risk was distant, a primacy was placed on gender. When risk was coming into focus, both gender and risk were ontologically highlighted. And, when risk was ever present, risk took centre stage with gender firmly placed in the shadows. In response to the creation and circulation of the gendered and risky HPV-related subject formations – which attempt to keep women "in order" and prompt them to "follow orders" women re-ordered *their* lives. Re-ordering, then, undermines order and provides the potential to enact power. What sales/governance strategies have tried to fix, the women interviewed continually unfixed.

Women's accounts of situated risk and gender also indicated that women were engaged in ontological decision making when deciding whether or not to get vaccinated or to have their daughters vaccinated. As women re-ordered, they were also "doing." Mothers were doing mothering, students were doing gender politics and intermittent risk, and patients were living with risk. In carrying out each aspect of "doing," women wove nets of experiences, which when assembled helped form their ethical being or sense of self. The knowledge accumulated through situated risk and gender experiences was then layered to form vaccination decisions. Correspondingly, decision making was not a discrete event, but an unfolding process. Ontological decision making was an inherently social and cultural process embedded in women's experiences of finding meaning in their efforts to be good mothers, strong young women merging into adulthood who also felt vulnerable to sexual health negotiation, and pre-cancerous patients seeking a "pause" amid the anxiety of seemingly never ending cycles of medical procedures.

B] Theoretical Contributions

In terms of theoretical contributions, this research project makes its greatest impact on the medical anthropology record in delivering a critical ethnographic account of situated risk *and* gender. However, as a by-product of this focus, four other significant findings have come to the fore:

1) *Sales/governance strategies* – This research project, through the case study of the HPV vaccine, highlights how corporations and governments work hand and hand to set public health policy in the neoliberal era of the new public health. Merck Frosst and the governments of Canada and Ontario deployed vaccine marketing, information and public health programming to influence women to be vaccinated through self-regulation. This individualized approach facilitated the sale of the vaccine and reinforced the governance tenets of the new public health, which emphasizes a self-disciplining approach to regulating "populations." Both Merck Frosst and the governments of Canada and Ontario framed HPV as a "woman's issue" by cleverly harnessing circulating and hegemonic cultural ideals surrounding risk and gender. The gendering of HPV aided in creating a "need" for the vaccine and the related in-school vaccination programming.

2) *Generative pause* – In researching situated risk and gender, it became clear that when women spoke about their experiences of navigating risk, gender and the vaccine, the pause they experienced during interviews was indeed a generative moment. Not only

were interviews times of contemplation, they were productive events. Mothers and students ruminated and processed how HPV infection and HPV vaccine risk was being transmitted by governmental and pharmaceutical discourses and how they were hybridizing or rejecting these messages. However, women were communicating much more than their vaccine decision making process during interviews. When taking a pause, each woman created a narrative that contributed to her continually developing sense of self. As each narrative developed, identity was re-inscribed and re-enforced, for it was in the thick of the pause that the exterior subject formation imposed by pharmaceutical and governmental discourses and interior realizations/actualizations of the self intersected. Women are not always portrayed as "doers" or those who do and in the case of HPV infection and the vaccine women are positioned as passive recipients and bearers of disease. It is in the space of the pause that women actively, continually and complexly negotiated their sense of self while working to secure their health vis-à-vis HPV infection and the HPV vaccine.

3) *The productive re-ordering of risk and gender* – It is important to note that women were not reinforcing the gendered at-risk subject formation of pharmaceutical and governmental discourses when they were doing mothering, doing gender politics and intermittent risk and doing risk. Sales/governance strategies attempt to order individuals or groups. In response, women re-ordered *their* lives. Re-ordering presents both a threat to order and the potential to enact power. Thus, while "doing", women were creatively re-appropriating/rejecting and hybridizing the gendered and risky HPV subject

formation to productive affect. As a result, the women of each cohort were doing their making of self differently depending on their context. Mothers ironically played with the concept of the good mother, students rejected mainstream concepts of gender and risk when saying “no” to the vaccine, and patients took a step back from the HPV treadmill when deciding to be vaccinated and set their own parameters to contain HPV. Each woman was doing this in her own way. Women did not exhibit one universal formula for interpreting gender and risk that mirrored the flat and totalizing way in which gendered risk is constructed and deployed in pharmaceutical and governmental policy discourses vis-à-vis the HPV vaccine.

4) *Ontological decision making* – In demonstrating how women made vaccine decisions based on their risk and gender-related negotiation experiences and not on linear-cost benefit analysis, this research project departs from existing literature in regard to risk related decision making. Current risk decision making research posits that decision making is teleological (see Austin et al. 2013; Jacobson et al. 2007; Poland et al. 2009; Poland and Jacobson 2001) and a “rational” and individual act. However, this approach does not recognize that decision making is an inherently social and cultural process. In the case of the women of my study, such a process of decision making was embedded in their experiences, whether as mothers trying to be good mothers, strong young women merging into adulthood, or pre-cancerous patients seeking a “pause” amid the stress of protracted medical procedures.

Either combined or used independently, the four concepts of sales/governance strategies, the generative pause, the productive re-ordering of risk and gender, and ontological decision making provide novel frames through which to engage in and analyze situated risk and gender research.

C] Future Pragmatic Research and Policy Considerations

From a policy perspective, not much has changed since the Public Health Agency of Canada released its report in 2005 entitled *Canadian Human Papillomavirus Vaccine Priorities Workshop*, which called for further Canadian research on HPV and the vaccine. While carrying out this research project – from the fieldwork to analysis stages – many research voids became glaringly apparent. As such, it is recommend that research, leading to renewed policy objectives, be pursued in the following thematic and pragmatic areas:

1) Middle school and high school aged boys/young men, girls/young women and those across the gender spectrum should take part in research concerning their conceptualizations of HPV and the HPV vaccine, not only in terms of sexual health, but the gendering of the virus and vaccine. How they process and find meaning within publicly circulating HPV and HPV vaccine knowledge is crucial in setting the baseline

data required to develop a de-gendered public information campaign regarding HPV and the vaccine.

2) Drawing upon the previous research initiative, develop, research and focus-group test sexual education materials regarding HPV and the vaccine to be included in middle school and high school curriculums that de-genders HPV and vaccine health communications.

3) Research and focus-group test public education materials regarding HPV and the vaccine among individuals across the gender spectrum, to be included in a generalized public health education campaign, that decouples gender from HPV.

4) Interview general practitioners regarding their perspectives on HPV and the vaccine. This research can be leveraged to develop follow-up information and dissemination protocols for patients receiving abnormal Pap test results from general practitioners in order to prevent the stigmatizing that women patients and students experienced in their medical encounters.

5) Conduct a larger, multi-sited research project across the province, which incorporates a greater diversity of women participants in terms of positionality. This type of project would analyze the impact of intersectionality (which could range from disability status to access to health insurance) on HPV infection experiences, vaccine

negotiation and cervical cancer prevention strategies, including Pap tests and post-HPV infection diagnosis medical interventions.

When and if these research and policy gaps are addressed, it will be interesting to follow changes in HPV vaccine programming in the future in Canada. In 2013 we have only reached the beginning of an academic conversation about the HPV vaccine and related policy. Policy is very slowly changing on the ground with the province of Prince Edward Island agreeing in the first half of 2013 to subsidize boys, along with girls, in school-based vaccination programs. Alberta was also in "discussion" during the summer of 2013 on this, but to date, an accompanying policy revision has not been made. These events may start to change the HPV vaccine conversation among public health policy and programming stakeholders across the country. However, the need to conduct research in the area of situated risk and gender will remain. While the specific medium through which gendered risk is deployed may change from that of the HPV vaccine to another medical "solution" or prevention strategy, the continued presence of sales/governance strategies will mean that women will be targets of risk, and have to live with risk, for years to come.

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Discography

Salt'N Pepper, Let's Talk About Sex © 1991 by Next Plateau Records, New York City.

Appendices

Appendix A - Glossary

Cervical dysplasia: According to the Canadian Cancer Society's web site, "dysplasia of the cervix means that abnormal changes have taken place in the cells of the cervix. It is usually picked up during [a] routine Pap test." (2011:1).

Cervarix®: A vaccine produced by GlaxoSmithKline that prevents infection by HPV strains 16 and 18, which cause cervical cancer. The vaccine is administered in three doses at zero, one and six month intervals (Product Monograph, GlaxoSmithKline 2012).

Cervical dysplasia grades: Cervical dysplasia, or cervical intraepithelial neoplasia, is classified by grades, which run from CIN (grade 1) to CIN 2 (grade 11) to CIN 3 (grade 111). CIN is considered mild, CIN 2 moderate and CIN 3 severe. CIN 3 can also be referred to as carcinoma in situ (Miller 1999). Abnormal Pap smears do not necessarily progress from CIN 1 to CIN 3 in a teleological fashion. Sometimes dysplasia clears on its own, or comes back at a different grade; various grades can co-exist (Agorastos et al. 2005).

Colposcopy: An examination of the cervix that is undertaken after an abnormal Pap test result. Sometimes the physician will take a small biopsy of cervical tissue during a colposcopy to access the severity of cell change (University Health Services, UC, Berkeley 2010).

Gardasil®: A vaccine produced by Merck Frosst to prevent infection of HPV strains 6, 11, 16, 18, which are related to genital warts and cervical cancer. The vaccine is administered in three doses over six months (Information about Gardasil®, Merck Frosst 2013).

GP: General practitioner, a physician who works as a family doctor.

GBA: Gender-based analysis.

Genital warts: Genital warts affiliated with HPV present on the penis, vagina, vulva, cervix and occasionally in the throat. They are spread through skin-to-skin contact and can be hard to detect. Various treatments can be implemented, including freezing or using acid or podophyllin to remove the warts (Facts about genital warts, Laurier University Health Services 2013).

HPV: Human Papillomavirus.

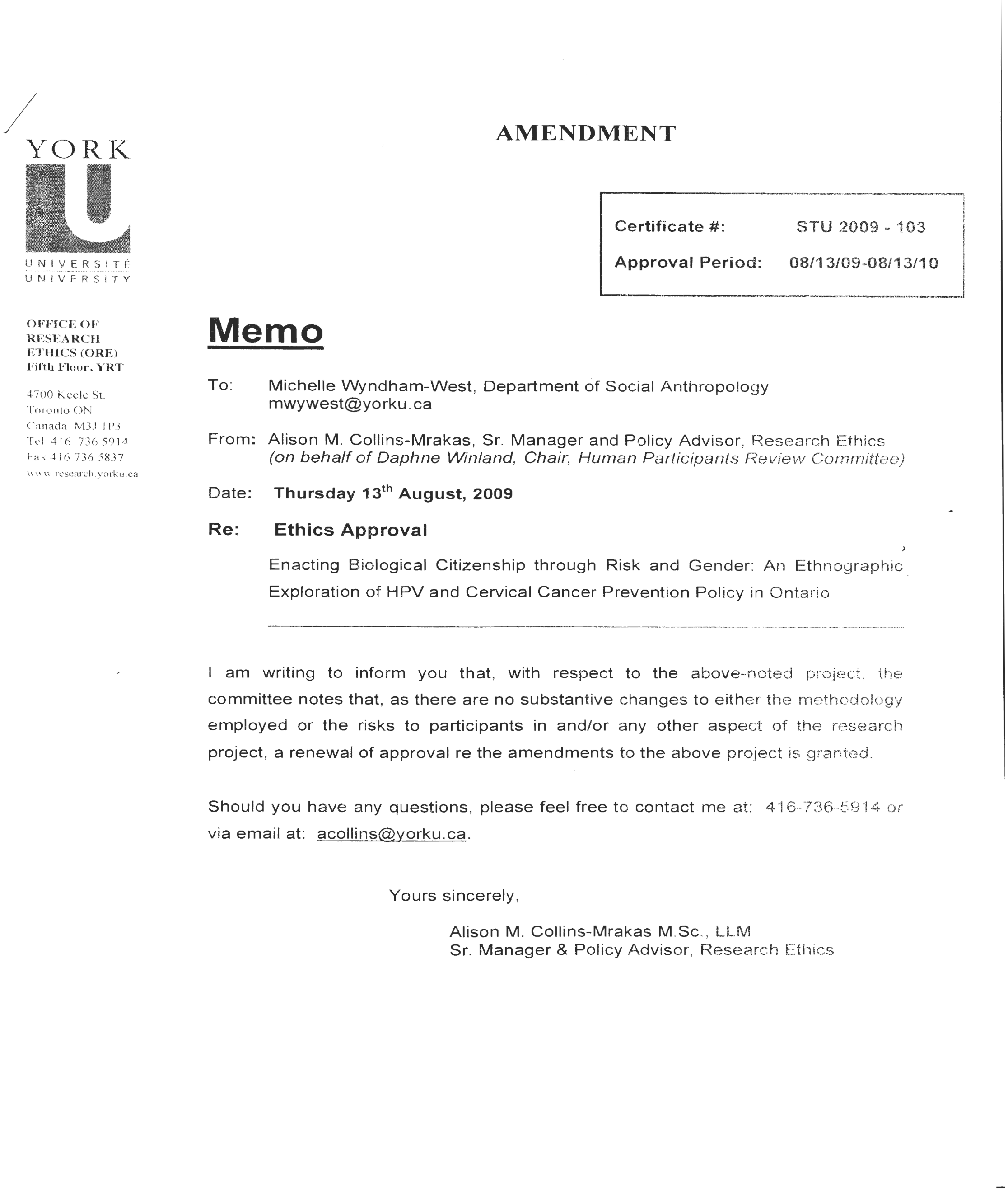
LEEP: An acronym for Loop Electrosurgical Excision Procedure, which is a process whereby "a circular or other shaped wire electrode [is used to] excise (remove) abnormal tissue on the cervix" (University Health Services, UC, Berkeley 2010:2).

NACI: National Advisory Committee on Immunization.

STI: Sexually transmitted infection.

Summary Basis of Decision: The document released by Health Canada when it has approved a pharmaceutical product for use in Canada

Appendix B – York University Ethics Approval



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AMENDMENT

Certificate #:	STU 2009 - 103
Approval Period:	08/13/09-08/13/10

Memo

To: Michelle Wyndham-West, Department of Social Anthropology
mwywest@yorku.ca

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics
(on behalf of Daphne Winland, Chair, Human Participants Review Committee)

Date: **Thursday 13th August, 2009**

Re: Ethics Approval

Enacting Biological Citizenship through Risk and Gender: An Ethnographic Exploration of HPV and Cervical Cancer Prevention Policy in Ontario

I am writing to inform you that, with respect to the above-noted project, the committee notes that, as there are no substantive changes to either the methodology employed or the risks to participants in and/or any other aspect of the research project, a renewal of approval re the amendments to the above project is granted.

Should you have any questions, please feel free to contact me at: 416-736-5914 or via email at: acollins@yorku.ca.

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LLM
Sr. Manager & Policy Advisor, Research Ethics

Appendix C – Sunnybrook Research Ethics Application

REB ID NUMBER:	**(office use only**

Toronto Academic Health Sciences Network (TAHSN)

HUMAN SUBJECTS RESEARCH APPLICATION

All sections of this application MUST be completed before it will be considered for REB review. A complete application must be submitted to each site where this research will take place. A separate detailed protocol must be included with each application. See TAHSN Guidelines for Research Ethics Review Involving Human Subjects.

SECTION I: GENERAL INFORMATION

1. PRINCIPAL INVESTIGATOR NAME*

* If your institution requires the PI to be a staff member, the on-staff investigator accepts the role and responsibilities of PI at this institution.

Title (e.g. Dr.): Dr.	**Last Name:** [redacted]	**First Name:** [redacted]

2. FULL STUDY TITLE

An Ethnographic Exploration of HPV and Cervical Cancer Prevention Policy in Ontario
Sponsor Protocol Number (if applicable):

2A. Is this protocol directly related to a previously approved study at this institution (e.g., extension, rollover, subsequent to a pilot study)? ☐ Yes ☒ No

If Yes, indicate name of Principal Investigator: n/a **and REB file number:** n/a

3. SOURCE OF FUNDING

Sponsor Name:	n/a
Granting Agency Name:	n/a
Internal Funding:	n/a
Other:	n/a
☐ **Funding obtained**	
☐ **Funding applied for**	**Expected date of decision:** n/a
☒ **No funding required**	**Explain:** n/a

4. INVESTIGATORS

4A. PRINCIPAL INVESTIGATOR CONTACT INFORMATION AND SIGNATURE

PRINCIPAL INVESTIGATOR AGREEMENT – I assume full responsibility for the scientific and ethical conduct of the study as described in this application and submitted protocol and agree to conduct this study in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Human Subjects and any other relevant regulations or guidelines. I certify that all researchers and other personnel involved in this project at this institution are appropriately qualified or will undergo appropriate training to fulfill their role in this project.

Dept/Div: Obstetrics & Gynecology	**Program:** Women & Babies	**Institution:** Sunnybrook & Women's College Health Sciences Centre **Room Number:** [redacted]
Telephone: 416-[redacted] [redacted]	**Pager:**	**Fax:** 416-[redacted]
Street Address: 76 Grenville Street		
City: Toronto	**Province:** Ontario	**Email:** [redacted]
Signature of Principal Investigator	**Date**	

4B. CO-INVESTGATOR(S) CONTACT INFORMATION AND SIGNATURE

CO- INVESTIGATOR AGREEMENT – I agree to participate in this study as described in this application and submitted protocol and agree to conduct this study in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Human Subjects and any other relevant regulations or guidelines.

1	Title: Ms.	Last Name: Wyndham-West	First Name: Michelle	Institution: York University
	Dept/Div: Anthropology	Program: PhD	Signature	
2	Title:	Last Name:	First Name:	Institution:
	Dept/Div:	Program:	Signature	
3	Title:	Last Name:	First Name:	Institution:
	Dept/Div:	Program:	Signature	
4	Title:	Last Name:	First Name:	Institution:
	Dept/Div:	Program:	Signature	
5	Title:	Last Name:	First Name:	Institution:
	Dept/Div:	Program:	Signature	

4C. CONTACT PERSON FOR THIS APPLICATION IF NOT THE PRINCIPAL INVESTIGATOR (e.g. study coordinator, research administrative contact, research student, institutional liaison).

Not Applicable ☐

Contact's Role in Study: Co-Investigator

Indicate to whom correspondence should be mailed: ☐ PI ☒ Other

Title: Ms.	Last Name: Wyndham-West	First Name: Michelle
Dept/Div: Anthropology	Program: PhD	Institution: York University
Telephone: 905-841-7691	Pager: n/a	Fax: n/a
Street Address: 2054 Vari Hall, 4700 Keele Street		
City: Toronto	Province: Ontario	Email: mwywest@yorku.ca

5. DEPARTMENT/DIVISION/PROGRAM APPROVAL*

* For institutions that require the PI to be a staff member, approval must come from the Department / Division / Program Head of the same institution as the PI.

DEPARTMENT/DIVISION/PROGRAM HEAD APPROVAL – I am aware of this proposal and support its submission for ethics review. I consider it to be feasible and appropriate. I attest that the Principal Investigator responsible for the conduct of this study is qualified by education, training, and experience to perform his/her role in this study.

Title:	Last Name:	First Name:
Signature of Dept/Div/Program Head	Date	

6. STUDY PERIOD

Expected start date: March 01/2010 **Total study duration:** 4 to 5 months

7. OTHER ETHICS/SCIENTIFIC/SCHOLARLY REVIEW

In order to facilitate the REB review process through harmonization and coordination of REB activity, identify if any of the REBs below have reviewed and/or approved the study outlined in this application (check all that apply):		***Ethics Review and Approval Status (check all that apply and indicate date where applicable):**			
		Application To Be Submitted	**Applied, Review Pending**	**Reviewed**	**Approved**
☐	Baycrest	☐	☐	☐	☐
☐	Bloorview Kids Rehab	☐	☐	☐	☐
☐	Centre for Addiction and Mental Health	☐	☐	☐	☐
☐	Hospital for Sick Children	☐	☐	☐	☐
☐	Mount Sinai Hospital	☐	☐	☐	☐

☐	St. Michael's Hospital	☐	☐	☐	☐
☐	Sunnybrook Health Sciences Centre	☐	☐	☐	☐
☐	Toronto Rehabilitation Institute	☐	☐	☐	☐
☐	University Health Network	☐	☐	☐	☐
☐	University of Toronto	☐	☐	☐	☐
☐	Women's College Hospital	☐	☐	☐	☐
☒	Other (e.g. Hamilton Health Sciences REB, University of Western Ontario Health Sciences REB, other GTA hospitals): York University	☐	☐	☒	☒ Aug. 13/09

Include all relevant correspondence related to ethics and scientific review (e.g. REB review letter, replies, approval letter).

8. CLINICAL TRIAL APPLICATION
This section must be completed for clinical trials only. See TAHSN guidelines for Health Canada's definition of a clinical trial.
Not applicable ☒ If not applicable proceed to Question 10.

8A. If this study involves any of the following, check all that apply:

☐ Investigational drug(s) - drug name(s):
☐ Approved drug for new indication, dosage, or formulation (e.g. new patient population) - drug name(s):
☐ Investigational biologics – name(s) of biologics:
☐ Investigational natural health products (NHP) – NHP name(s):
☐ Investigational medical devices – device name(s):

8B. If this study involves submission to Health Canada under the Food and Drug Act:
Is Health Canada "No objection letter" or regulatory authorization attached? ☐ Yes ☐ No
If No, when is it expected?

8C. Provide the FDA IND number (drug studies) or PMA number (device studies):
FDA IND #: ☐ Pending
PMA #: ☐ Pending
Not Applicable ☐

Note: final approval will not be granted until the appropriate regulatory approval has been received.

9. CLINICAL TRIAL REGISTRATION
The International Committee of Medical Journal Editors (ICJME) has indicated that clinical trials will not be published without the registration of that trial prior to subject enrolment. A clinical trial

is defined by ICJME as, "Any research project that prospectively assigns human subjects to intervention and comparison groups to study the cause-and-effect relationship between a medical intervention and a health outcome. This definition includes drugs, surgical procedures, devices, behavioural treatments, process-of-case changes and the like. A trial must have at least one prospectively assigned concurrent control or comparison group in order to trigger the requirement for registration."

Given the above definition, indicate whether this trial will be registered (e.g., www.clinicaltrials.gov, www.controlled-trials.com/isrctn/). ☐ Yes ☐ No ☐ Not Applicable

If Yes, provide registration site:

SECTION II: STUDY SUMMARY

Note: Responses to this section are not a substitute for the full protocol.

10. ABSTRACT

Must be summary of study suitable for lay audience.

(Max ¼ page)
I am conducting an ethnographic study of Ontario's cervical cancer prevention policy, including the HPV vaccine, as an example of the networks of public health policy. Critical to this study is the collection and analysis of health policy narratives as they are developed across institutions and received, refuted or amalgamated by women in their everyday lives. In examining these narratives, I am focusing on notions of risk vis-à-vis HPV and cervical cancer. The objective is to gain a greater understanding of how Ontario-based women negotiate cervical cancer risk, particularly since the introduction of the HPV vaccine. The research is being conducted over three sites, the third of which pertains to Sunnybrook. The sites include: (1) textual/archival analysis of institutional risk narratives; (2) interviews with moms negotiating their cervical cancer risk and the HPV vaccine for their daughters; and (3) interviews with women attending Sunnybrook's HPV clinic.

11. RATIONALE AND HYPOTHESIS/RESEARCH QUESTION

11A. Indicate the rationale for this study.

(Max ¼ page)(

The objective of the research is to gain a greater understanding of how Ontario women negotiate cervical cancer risk, particularly since the introduction of the HPV vaccine. It is important to gauge the effect of increasing HPV awareness and the HPV vaccine on day-to-day cervical cancer risk prevention practices. Existing literature (Ogilvie, et al, 2007; Dempsey, et al, 2006), does not explore women's responses to HPV and the HPV vaccination in an in-depth manner. Further, the Public Health Agency of Canada identified the need to research, from a social science perspective, the "knowledge, attitudes and beliefs" of parents and young women regarding the HPV vaccine (2005:iv). This qualitative research project begins to fill that gap by directly exploring "the complexity of women's responses…, which may range from selective resistance to selective compliance" (Lock & Kaufert, 1998:2).

11B. Indicate the hypothesis for this study or research question.

(Max ¼ page)
Research Question Pertinent to Sunnybrook: Since the concretization in medical science of the linkage

between HPV and cervical cancer and the introduction of the HPV vaccine, how are Ontario-based women negotiaitng cervical cancer risk in their everyday lives?

11C. Indicate the significance of the study (i.e. the overall anticipated public and/or scientific benefit).

(Max ¼ page)
In addition to filling a void in the academic literature concerning HPV and cervical cancer risk negotiation, this project will have direct relevance to the medical and public health communties. The research will provide in-depth data regarding the knowledge, attitudes and beliefs of Ontario-based women regarding HPV, the HPV vaccine and cervical cancer screening practices in general. This data can be applied to cervical cancer screening program planning and related public health promotion.

12. STUDY DESIGN

Many of these questions apply to clinical research studies. If any of the items are not applicable to your study, indicate N/A.

12A. Describe the design and methodology (e.g. pre/post design, pilot, study visits, procedures, study intervention).

(Max ½ page)
I am implementing the research project in three phases as mentioned in section 10. The third phase is relevant to Sunnybrook. In the third phase, I will focus upon women's narratives as they negotiate the province's cervical cancer prevention policy. In this phase , interviews will be conducted with a cohort of 20-25 young women who are clients of the HPV clinic at Sunnybrook Health Sciences Centre. These women are negotiating their own cervical cancer risk, with an emphasis on the HPV vaccine. This stage has been developed in consultation with Dr. [redacted] and [redacted], RN (EC). Interviews with Sunnybrook clients will take place over the telephone or in person on a convenient date after a clinic visit. All interviewees will be over 16 years of age and will provide informed consent. Informed consent will be obtained by nursing staff and the interviews conducted by Michelle Wyndham-West, PhD Candidate, York University. The qualitative data will be unpacked through a "categorical-content" type of narrative analysis (Lieblich, et al, 1998:13).

12B. Describe the primary outcome measures/goals of the study.

(Max ¼ page)
The goal of the research is to gain a greater understanding of how Ontario-based women negotiate cervical cancer risk, particularly since the introduction of the HPV vaccine. This will be assessed by gathering and analyzing qualitative data addressing knowledge, attitudes and beliefs concerning HPV, the HPV vaccine and cervical cancer risk prevention practices. Data gathered will, specifically, provide in-depth accounts of : (1) risk perceptions vis-a-vis cervical cancer; (2) HPV awareness and HPV-centered knowledge; (3) detailed infromation regarding cervical cancer screening practices; and (4) decision-making surrounding the HPV vaccine.

12C. List any criteria for premature withdrawal of a subject from the study for safety concerns.

Not Applicable ☒

(Max ¼ page)
N/A

12D. Is a placebo used in this study? ☐ Yes ☒ No

If Yes, explain how this is this justified (e.g. no alternative standard treatment available). Include any provisions in place to reduce risks to subjects assigned to placebo (e.g., increased monitoring, rescue medication).

(Max ¼ page) N/A

12E. Does this study involve deception or intentional lack of disclosure? ☐ Yes ☒ No

If Yes, justify and indicate how subjects will be debriefed.

(Max ¼ page) N/A

12F. Will the subject be withdrawn from or denied usual therapy for any condition in order to participate in the study or be subject to other restrictions during the study? ☐ Yes ☒ No
(This would include medications that are prohibited or restricted in order to be eligible for the study or that may be prohibited or restricted during the course of the study.)

If Yes, explain.

(Max ¼ page) N/A

13. SUBJECT/CONTROLS

13A. Indicate the main inclusion/exclusion criteria.

(Max ¼ page) All clients 16 years of age or older of the HPV clinic will be eligible to take part in the research project. Clients under 16 years of age of the HPV clinic will not be eligible to take part in the research project.

i) Indicate the age range of eligible subjects: 16 years of age and older

13B. If applicable, indicate the rationale for control group(s).

(Max ¼ page) N/A

13C.

Total study enrollment: 20 to 25 clients of the HPV clinic	
Number of subjects to be enrolled at this institution: 20 to 25	**Indicate the time period for enrollment:** March to July, 2010
Approximate size of eligible population from institution/practice: Anticipate approximately 100 clients will attend the clinic during a five month period.	

13D. Is sample size justified in the protocol? ☒ Yes ☐ No

If Yes, indicate protocol page: 9

If No, provide sample size justification.

(Max ¼ page)
N/A

14. STUDY INTERVENTIONS OR PROCEDURES
Not Applicable ☒ (e.g. observational studies). If not applicable, go directly to 15. DATA ANALYSIS

14A. Document the usual standard of care at this institution for this population.
Not Applicable ☐

(Max ¼ page)
N/A

14B. Indicate what procedures are to be carried out in the study, that are not considered part of the diagnostic, therapeutic "routine" or indicate how standard of care is altered. Attach a copy of all non-standardized instruments (e.g., questionnaires, rating scales).

(Max ¼ page)
N/A

14C. Indicate the additional risks associated with the study as compared to usual standard of care. Do not refer to other sections of this form.

(Max ½ page)
N/A

14D. Indicate duration of study visits and extra time commitment (length, number, and frequency of test sessions) for study participation.

(Max ¼ page)
N/A

15. DATA ANALYSIS

Briefly explain what methods will be used to analyze study data.
References to protocol for this question are acceptable. Indicate applicable page(s) of protocol.

(Max ¼ page)
12

SECTION III: ETHICAL ISSUES

16. RECRUITMENT AND CONSENT
Not Applicable ☐

Note: Any document to be viewed by the subject (e.g., recruitment posters/letters, consent/assent forms, information sheets) must be included with your submission.

16A. Indicate what tools will be used to identify potential subjects for recruitment into the study.

☒ Permanent health record/clinical chart (specify source): HPV nursing staff will identify suitable interviewees to Michelle Wyndham-West. Michelle Wyndham-West will not have access to health records; this priviledge rests with nursing staff only.
☐ Existing database (specify): o Does the Principal Investigator maintain the database? ☐ Yes ☐ No o If No, identify the entity that maintains the database: Note: The creation and maintenance of a database for research purposes is a research activity that may require a separate REB application. Consult your institutional REB.
☒ Advertisements, including web based recruitment tools (attach)
☐ Other (specify):

16B. Indicate who will identify potential study subjects

☐ Investigator/study personnel
☒ Other healthcare professional (e.g. non-study personnel)
☒ Self-referral (e.g. response to advertisement)

i) Identify all persons who will be reviewing health records/identifying information (for recruitment purposes).

1	Title: Primary Health Care Nurse Practitioner	Last Name: [redacted]	First Name: [redacted]
	Institution: Sunnybrook	Qualifications: Rn (Ec), BScN, MSc, PHCNP	Role in Study: Identify potential interviewees and complete consent process
2	Title:	Last Name:	First Name:
	Institution:	Qualifications:	Role in Study:
3	Title:	Last Name:	First Name:
	Institution:	Qualifications:	Role in Study:
4	Title:	Last Name:	First Name:
	Institution:	Qualifications:	Role in Study:
5	Title:	Last Name:	First Name:
	Institution:	Qualifications:	Role in Study:

ii) List the identifying information that will be collected, used, or disclosed from the records during the course of the proposed recruitment activities.

☒ Name	☐ Images (e.g., photographic, x-ray, MRI scans)
☐ Address	☐ Social Insurance Number
☐ Telephone Numbers	☐ Medical Record Number
☐ Email Address	☐ Date of Birth
☐ Health Card Number	☐ Health Information: (e.g., relating to inclusion /exclusion criteria, medications)
☐ Other information (specify):	

iii) Describe the security measures that will be taken to protect the confidentiality of this information.

(Max ¼ page)
Michelle Wyndham-West has been identified as the designated person to ensure the confidentiality of identifying data during the recruitment period. It will be necessary to obtain contact details of recruits (i.e. telephone number) in order to arrange interviews. These will be provided by potential interviewees and not Sunnybrook. Sunnybrook will provide names only to Michelle Wyndam-West. All telephone numbers gathered during the recruitment will be kept at the HPV clinic, both in paper form in a locked cabinet and electronically on a secure server. During the recruitment process a key file will be created, which assigns a study number for each participant to serve as a future unique study identifier. The key file will be housed at the Sunnybrook HPV clinic, both in paper form in a locked cabinet and electronically on a secure server. The key file will not leave Sunnybrook.

iv) Indicate what will happen to this information at the completion of the recruitment process.

(Max ¼ page)
At the end of a completed interview (hence, the end of the recruitment process), the recruitment related data which can serve as identifying, i.e. telephone number, will be destroyed, both in paper and electronic form. Paper-based information will be shredded using Sunnybrook's shredding/disposal process and electronic data will be erased via the "Permanent Eraser" for Mac, which uses the Gutmann method.

16C. Indicate who will make initial contact with potential subjects or authorized third party, whether they are already known to the subject or authorized third party, and how contact will be made (e.g., in person, phone, letter, e-mail, website). Attach a copy of the script or any written materials if applicable.

(Max ¼ page)
Initial approach of patients will be undertaken by [redacted], RN (EC). Michelle Wyndham-West will follow-up with potential interviewees at the HPV clinic in person if they have expressed interest to [redacted]. Michelle Wyndham-West will answer all telephone enquiries from individuals responding to study recruitment posters. The study recruitment posters will be affixed in the HPV clinic. Michelle Wyndham-West will not be known to the prospective interviewees.

16D. Describe the consent process and who will obtain consent (e.g. will consent be written, oral, telephone (include script). If the study population requires special consent considerations (e.g., child, incompetent adult, unable to communicate), refer to 16E.

(Max ¼ page)
The consent process will be completed by [redacted], RN (EC), the staff nurse at the HPV clinic. The consent process will be completed during the HPV clinic hours while prospective interviewees are attending the HPV clinic. Prospective interviewees who have contacted Michelle Wyndham-West for study information by phone will be required to complete the consent process with [redacted] during clinic hours in person. The study population does not require special consent consideration as all interviewees will be over 16 years of age.

i) Indicate if there is a relationship between the subjects and either of the following:

Person obtaining consent ☒ Yes ☐ No
Investigator ☒ Yes ☐ No

ii) If Yes, explain the nature of the relationship (e.g., physician, employer) and what steps will be taken to avoid the perception of undue influence.

(Max ¼ page)
The nurse practitioner running the HPV clinic will be obtaining consent and the principal investigator of this research project is a physician at the HPV clinic. Michelle Wyndham-West, a PhD candidate at York University, will be conducting interviews. Michelle does not hold a relationship with clients at the HPV clinic, nor is she employed at the clinic, and this will lessen the perception of undue influence for prospective participants.

iii) Indicate how much time will be given to subjects to review the information before being asked to give consent.

(Max ¼ page)
Consent forms will be completed during an HPV clinic visit. The clinic operates every Wednesday afternoon. Prospective participants can use the duration of their clinic visit to provide consent and can also take the study information with them and return another Wednesday afternoon to complete the consent process.

16E. Indicate if the research will involve any of the following:

i) Special Considerations (check all that apply):

☒ Women of child bearing potential
☐ Pregnant women
☒ Healthy volunteers
☐ Students
☐ Staff
☐ Genetic research
☐ Tissue samples
☐ Fetal tissue or placenta
☐ Prisoners
☐ None of the above

ii) Capacity/Competency (check all that apply):

☐ Children less than 16 years of age
☐ Emergency patients
☐ Individuals temporarily unable to provide an informed consent
☐ Marginally incompetent subjects
☐ Incompetent subjects
☒ None of the above

Describe how capacity will be assessed for any individuals in 16Eii.

(Max ¼ page)
N/A

If subjects are incapable of providing consent, provide information on how substitute decision makers will be identified.

(Max ¼ page)
N/A

When inability to provide an informed consent is expected to be temporary, describe what procedures will be used to regularly assess capacity and to obtain consent if the individual later becomes capable of providing consent.

(Max ¼ page)
N/A

iii) Communication Difficulties (check all that apply):

☐ Individuals who may require translation
☐ Individuals who are illiterate
☐ Subjects unable to communicate
☒ None of the above

Provide an explanation of what procedures will be used to address any communication difficulties (e.g., the use of translated forms, translator, impartial witness).

(Max ¼ page) N/A

16F. If potential subjects might be approached for recruitment in other studies, indicate the steps that will be taken to minimize the number of times that this will occur.

(Max ¼ page) N/A

17. RISK/BENEFIT ESTIMATES

17A. Potential Benefits to Subjects

No direct benefits anticipated ☒

List anticipated benefits to the subject, if any.

(Max ¼ page) N/A

17B. Potential Harms (injury, discomfort and inconvenience) to subject (including psychological factors).

No known risks ☒

i) List the known risks of study intervention(s) including approximate rates of occurrence, severity and rates of reversibility.

(Max ¾ page) N/A

ii) List the risks of any tests, procedures or other protocol-mandated activities that are conducted for research purposes only, including approximate rates of occurrence, severity and reversibility.

(Max ¾ page) N/A

iii) For studies involving placebo, washout, or withholding treatment, list any risks related to absence of treatment.

Not Applicable ☐

(Max ¾ page) N/A

iv) Include a summary of the data regarding reproductive risks such as teratogenicity or embryotoxicity of the study drug, any risk with breastfeeding, or risk to men regarding conception.
Risks unknown ☐

(Max ¼ page) N/A

v) Indicate whether participation in this study affects alternatives for future care.
☒ Yes ☒ No

If Yes, explain.

(Max ¼ page) N/A

18. PAYMENTS

Not Applicable ☒

18A. Indicate what payment(s) will be provided to subjects or substitute decision makers, if applicable.

☐ Reimbursement for expenses incurred as a result of research Amount: N/A Specify (e.g., travel, meals): N/A
☐ Gifts for participation Value: N/A
☐ Compensation for time Amount: N/A Provide justification if compensation for time will be provided. (Max 1/4 page) N/A
☐ Other forms of compensation: N/A

19. MONITORING

19A. Indicate if there is a plan for monitoring of the study (e.g. sponsor initiated site visits)
☐ Yes ☐ No ☒ Not Applicable

If YES, describe.

(Max ¼ page) N/A

19B. Indicate if an interim analysis is planned. ☐ Yes ☐ No ☒ Not Applicable

If Yes, describe briefly.

(Max ¼ page) N/A

19C. Indicate if there is a steering committee. ☐ Yes ☐ No ☒ Not Applicable

If Yes, provide a copy of the terms of reference (mandate) of the steering committee.

19D. Indicate if there is a data and safety monitoring board (DSMB).
☐ Yes ☐ No ☒ Not Applicable

If Yes, forward a copy of the DSMB charter when available or provide a description of the DSMB, including its purpose, membership, relationship to the sponsor, and whether the committee will review unblinded study data etc. Refer to the protocol as needed.

(Max ¼ page) N/A

If No, justify and explain what alternative arrangements are in place to monitor the safety data and how the overall risk/benefit information will be communicated to the REB.

(Max ¼ page) N/A

20. POTENTIAL CONFLICTS OF INTEREST

If any of the conflicts listed below apply to any of the Investigators involved in the research study or any member of their immediate family, append a letter to the Chair of the REB detailing these activities and how they will be managed. Disclose all contracts and any conflicts of interest (actual, apparent, perceived, or potential) relating to this project. Conflict of interest may also arise with regard to the disclosure of personal health information.

☐ Function as an advisor, employee, officer, director or consultant for the study sponsor
☐ Have direct or indirect financial interest in the drug, device or technology employed in this research study (including patents or stocks)
☐ Receive an honorarium or other personal benefits from the sponsor (apart from fees for service)
☐ Receive direct or indirect financial benefit from the disclosure of personal health information
☐ Other
☒ None of the above

21. PUBLICATION/DISSEMINATION OF RESULTS

Indicate how the results will be communicated to subjects and other stakeholders (e.g., advocacy groups, scientific community).

☐ Individual debriefing at end of test session	☒ Publication
☐ Group debriefing	☐ Other (specify):
☐ Letter of appreciation at end of study	☐ No Plan

If no plan is in place, provide justification.
Not Applicable ☒

(Max ¼ page) N/A

SECTION IV: PRIVACY AND CONFIDENTIALITY

22. COLLECTION USE AND DISCLOSURE OF PERSONAL HEALTH INFORMATION

Investigators should comply with the duties set out for researchers in the Personal Health Information Protection ACT (PHIPA – effective in Ontario Nov. 1, 2004) and with the privacy and confidentiality and consent guidelines outlined in theTri-Council Policy Statement on Ethical Conduct for Research Involving Humans.

22A. List all personal health information and personal identifiers (e.g. name, DOB) required to be collected. For all non-clinical trials, attach data collection forms.

(Max ¼ page)
Personal identifiers to be collected include: name and phone number.

22B. Identify all potential sources of this information.

(Max ¼ page)
The names of prospective interviewees will be given to Michelle Wyndham-West, PhD Candidate, York University, by [redacted], RN (EC). Contact details (i.e. telephone number) of prospective interviewees will be given by the prospective interviewees themselves to Michelle Wyndham-West.

22C. Indicate how study subjects will be identified on data collection forms (e.g. study number, initials).

(Max ¼ page)
A key fille will be created, which attributes a unique study number to each participant. This key fille will reside at Sunnybrook only, in a locked cabinet for the paper copy and on a secure Sunnybrook server for the electronic copy. All data regarding research particpants will be coded as per their unique study identifier and stored in a different location than the key file.

22D. Indicate how data will be stored.

☐ Computerized files (specify): Server ☒ Desktop ☒ Laptop ☒
☒ Audio recordings
☒ Hard copy
☐ Videotape
☐ Other (e.g. PDA): N/A

i) Describe the safeguards to protect the confidentiality and security of the data, including any physical and technical safeguards (e.g. data will be stored in a locked and secure area, the data will be stored on a secure server that is password protected)

(Max ¼ page)
Research data, with unique study numbers will be kept at Michelle Wyndham-West's residence. This will ensure that research data is kept in a different location than the key file. All forms of study data, including audiotapes and transcribed versions of the interviews will be kept on an encrypted USB key at Michelle Wyndham-West's residence. Back-up copies of the data, which will be in paper form, will be kept in a locked filing cabinet in Michelle Wyndham-West's home. All research data will be desroyed after five years as per Sunnybrook's policy. Hard copy data will be shredded and disposed of as per Sunnybrook policy and all electronic data will be erased permanently using "Permanent Eraser" for Mac, which uses the Gutmann method.

ii) Indicate who will have access to these data in the future.

(Max ¼ page)

Research data will be available to Dr. [redacted] and [redacted], RN (EC). Research data will be de-identified and include unique study numbers.

22E. Indicate if any information that could potentially identify study subjects will be disclosed outside of the institution (e.g., names, initials, DOB, OHIP #).
☒ Yes ☐ No

If Yes, justify and describe how this information will be transferred and any security measures to be used (e.g., anonymized data, secure network upload or download).

(Max ¼ page) Michelle Wyndham-West will gather names and contact information of prospective interviewees while at the HPV clininc. This information will be given to Michelle Wyndham-West from the interviewees themselves and after informed consent has been obtained by nursing staff. This information will reside on Michelle Wyndham-West's laptop in order to be able to arrange interviews. This data will be encrypted on Michelle Wyndham-West's laptop in order to ensure the security of the data. Once an interview has been completed an interviewee's name and contact details will be removed from the said laptop using the "Permanent Eraser" for Mac, which uses the Gutmann method.

22F. If personal health information is to be linked to other databases (e.g., health registries, statistics Canada information) provide the following details:
Not Applicable ☒

i) Describe the data to which the personal health information will be linked.

(Max ¼ page) N/A

ii) Explain how the linkages will be made.

(Max ¼ page) N/A

iii) Explain why these linkages are required.

(Max ¼ page) N/A

22G. Indicate how long the personal health information will remain identifiable and explain why.
Not Applicable ☐

(Max ¼ page) Personal information, comprising soley of name and telephone number, will only remain identifiable during the recruitment of an interviewee. Once the interview is complete, this personal information will be removed form Michelle Wyndham-West's encrypted laptop via the "Permanent Eraser" for Mac function and remain solely with the key file at Sunnybrook. It is vital to have an interviewees name and contact details in order to arrange and complete an interview. Once the interview is complete, there is no need for this information to reside outside the key file.

22H. Identify all persons (in addition to those listed in Q. 16Bi) that will have access to the personal health information, their roles in the study, their reason for access, and related qualifications.

1	Title: N/A	Last Name:	First Name:
	Institution:	Qualifications:	Role in Study:
2	Title:	Last Name:	First Name:
	Institution:	Qualifications:	Role in Study:
3	Title:	Last Name:	First Name:
	Institution:	Qualifications:	Role in Study:
4	Title:	Last Name:	First Name:
	Institution:	Qualifications:	Role in Study:
5	Title:	Last Name:	First Name:
	Institution:	Qualifications:	Role in Study:

22I. Explain why the research cannot reasonably be accomplished without using personal health information.

(Max ¼ page)

The only personal health information to be obtained from prospective interviewees will be their names and telephone numbers for recruitment purposes. Withouth this information, it would be impossible to arrange an interview.

22J. If personal health information will be collected, used or disclosed without consent from the individuals to whom the information relates, explain why obtaining explicit consent would be impractical.

(Max ¼ page)

Informed consent will be obtained from individuals in order to gather their names and telephone number with the aim of arranging an interview.

22K. Describe any harms or benefits that could arise if personal health information was inappropriately released (e.g., embarrassment, refusal of employment or insurance coverage, stigmatization of individuals / groups) and how any consequences would be addressed.

(Max ¼ page)

Research data will be attributed unique study numbers and reside in encrypted form on Michelle Wyndham-West's laptop and on an encrypted USB key in order to mitigate the risks of inappropriately released personal health information. Once audio files of interviews have been downloaded to the encrypted USB key, the original audio recording, which was recorded on a hand-held recording device, will be destroyed by deleting the recording. The key file will not leave Sunnybrook and will reside on a secure server. Interviews do not aim to collect any data that can put a participant at risk of embarrassment, refusal of employment or insurance coverage or stigmatization.

22L. Describe how and when the personal health information will be disposed of or returned to the health information custodian.

(Max ¼ page)

Personal health information, including solely names and telephone numberss, will be destroyed once an interview is complete, save for this information in the key file, which will reside at Sunnybrook. The personal health information will be removed from Michelle Wyndham-West's encrypted laptop once an interview is complete using the "Permanent Eraser" for Mac function.

SECTION V: FUNDING AND CONTRACTS

23. BUDGET

☒ **No budget required**

Attach an itemized study budget (applies to all full board and expedited review studies). The budget should reflect all costs at this institution.

Indicate whether the funding is sufficient to cover all study costs. ☐ **Yes** ☐ **No**

f No, explain how the shortfall will be made up.

(Max ¼ page)
N/A

Indicate if any investigator will receive direct personal payments from the budget. ☐ Yes ☒ No

If Yes, describe what these payments are for and the amount.

(Max ¼ page)
N/A

24. AGREEMENTS

24A. Contract/Research Agreement

Indicate whether there is a contract/research agreement involved ☐ Yes ☒ No

If Yes, provide name of sponsor/agency:
Provide name of the contract research organization: Not applicable ☒

24B. Indicate whether the contract/research agreement has been submitted for review and signing. (See institution specific instruction page) ☐ Yes ☒ No

24C. Indicate if there is external (non-institutional) liability insurance. ☐ Yes ☒ No

ii) Indicate who will cover reasonable out-of pocket expenses to ensure that immediate medical care is provided if a subject suffers an injury as a result of participation in the study.

☐ Sponsor
☐ Institution
☐ Other (specify): N/A

24D. Publication Agreements

i) Indicate if there is an agreement between the Investigator and the sponsor regarding the use, publication or disposal of the data. ☐ Yes ☒ No ☐ Pending

ii) If Yes, Indicate whether the funding agency or sponsoring company places any restrictions on publication of findings or reporting interim results. ☐ Yes ☒ No ☐ Pending

iii) If Yes, explain any restrictions.

(Max ¼ page) N/A

25. MATERIAL TRANSFER AGREEMENT

Indicate if there is a material transfer agreement (MTA) involving human material for this study. This refers to an agreement for transfer of biological materials (e.g. tissues, cell lines) from the institution to another institution or entity. ☐ Yes ☒ No

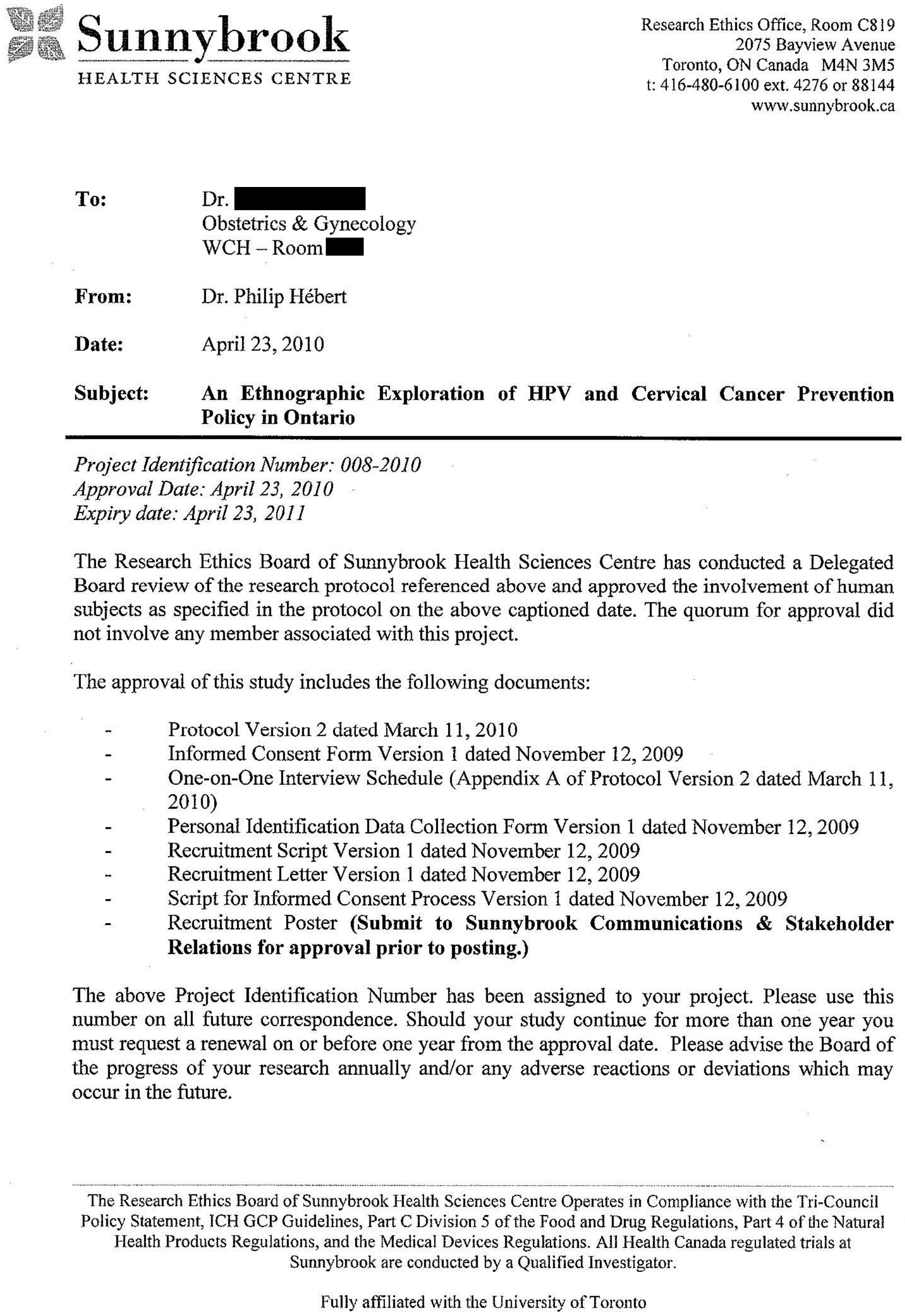
If Yes, attach a copy of the agreement.

26. INFORMATION SHARING

Indicate if there is an information sharing agreement. ☐ Yes ☐ No

If Yes, attach a copy of the agreement.

Appendix D – Sunnybrook Approval Letters



Sunnybrook
HEALTH SCIENCES CENTRE

Research Ethics Office, Room C819
2075 Bayview Avenue
Toronto, ON Canada M4N 3M5
t: 416-480-6100 ext. 4276 or 88144
www.sunnybrook.ca

To: Dr. [redacted]
Obstetrics & Gynecology
WCH – Room [redacted]

From: Dr. Philip Hébert

Date: April 23, 2010

Subject: **An Ethnographic Exploration of HPV and Cervical Cancer Prevention Policy in Ontario**

Project Identification Number: 008-2010
Approval Date: April 23, 2010
Expiry date: April 23, 2011

The Research Ethics Board of Sunnybrook Health Sciences Centre has conducted a Delegated Board review of the research protocol referenced above and approved the involvement of human subjects as specified in the protocol on the above captioned date. The quorum for approval did not involve any member associated with this project.

The approval of this study includes the following documents:

- Protocol Version 2 dated March 11, 2010
- Informed Consent Form Version 1 dated November 12, 2009
- One-on-One Interview Schedule (Appendix A of Protocol Version 2 dated March 11, 2010)
- Personal Identification Data Collection Form Version 1 dated November 12, 2009
- Recruitment Script Version 1 dated November 12, 2009
- Recruitment Letter Version 1 dated November 12, 2009
- Script for Informed Consent Process Version 1 dated November 12, 2009
- Recruitment Poster **(Submit to Sunnybrook Communications & Stakeholder Relations for approval prior to posting.)**

The above Project Identification Number has been assigned to your project. Please use this number on all future correspondence. Should your study continue for more than one year you must request a renewal on or before one year from the approval date. Please advise the Board of the progress of your research annually and/or any adverse reactions or deviations which may occur in the future.

The Research Ethics Board of Sunnybrook Health Sciences Centre Operates in Compliance with the Tri-Council Policy Statement, ICH GCP Guidelines, Part C Division 5 of the Food and Drug Regulations, Part 4 of the Natural Health Products Regulations, and the Medical Devices Regulations. All Health Canada regulated trials at Sunnybrook are conducted by a Qualified Investigator.

Fully affiliated with the University of Toronto

Approval of this study by the Sunnybrook REB entails that this study complies with current legislation as outlined in the Ontario Personal Health Information Protection Act (PHIPA) and all policies and guidelines established by Sunnybrook Health Sciences Centre. All applicable contracts and agreements must be submitted to Sunnybrook Research Administration before this research may be initiated.

Philip C. Hébert, MD PhD FCFPC
Chair, Research Ethics Board
/tt

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Research Ethics Office, Room C819
2075 Bayview Avenue
Toronto, ON Canada M4N 3M5
t: 416-480-6100 ext. 4276 or 88144
http://sunnybrook.ca/research/?page=reohome

To: Dr [redacted]
Obstetrics & Gynecology
WCH – [redacted]

From: Dr. Philip Hébert

Date: March 9, 2010

Subject: **An Ethnographic Exploration of HPV and Cervical Cancer Prevention Policy in Ontario**

The Research Ethics Board conducted a Delegated Board review of the above referenced study.

The Board has the following comments for your consideration with regards to this study.

1. Question 22D and 22E of the application describe how data will be stored. It is the policy of the Sunnybrook Privacy Office that the hard drives of all laptops are encrypted as encryption of individual files is not sufficient.
    a. If this is not possible, all electronic data that leaves Sunnybrook must be stored on an encrypted USB key. Please comment.
    b. The REB requests that no hard copy data leaves Sunnybrook. However, if this is not possible the data should not include any identifiable information or personal health information. Please comment.

2. Please clarify how the study nurse will determine who to approach about this study. Will every patient be approached as they present within the clinic?

To enable us to complete our review of this study, please provide a response to each comment in a letter to the Chair and forward, along with a copy of all revised documents, to the Research Ethics Office, Room C8 19. We look forward to hearing from you and to approving your study.

Philip C. Hébert, MD PhD FCFPC
Chair, Research Ethics Board
/tt

OR

Blair Henry,
Vice-Chair, Research Ethics Board

Appendix E –Interview Schedule

MICHELLE WYNDHAM-WEST, PHD DISSERTATION RESEARCH - DRAFT ONE-ON-ONE INTERVIEW SCHEDULE

Background:

Start off asking basic demographic information to open up the conversation (I can also explain a bit about my background if this would help in making people at ease, but the focus should remain on the interviewees)

- Are you single or in a long-term relationship? If you have a partner, please describe his/her background.
- How old are you?
- What is your occupation? (i.e. Are you a student? What are you studying? Do you work part-time or full-time? What area do you work in?)
- Please describe your educational history.
- How would you describe your religious affiliation? This includes not feeling attached to a particular religion and organized forms of religious practice.
- How would you describe your ethnic background?

Risk, cervical cancer & HPV:

- Why do you think people get cancer? Please list some of the reasons/factors that you think come into play when getting cancer.
- Where did you learn about these risks? (Family, friends, media, doctor, nurse, other sources, etc.)
- Why do you think women get cervical cancer? Please list some of the reasons/factors that you think come into play when getting cervical cancer. (Possible prompts can include genetics, lifestyle, sexual activity, HPV, environmental influences, etc.)
- Where did you learn about cervical cancer risks? (Family, friends, media, doctor, nurse, other sources, etc.)
- Do you think cervical cancer can be prevented? If so, how? If not, why not?
- Are there particular activities women can engage in or not engage in to prevent from getting cervical cancer? Do you take part or not take part in these activities in order to prevent cervical cancer?
- How would you describe HPV? (i.e. How does a person get HPV? What happens when they get HPV?)
- How do you think HPV is linked to cervical cancer?
- How has recent attention to the links between HPV and cervical cancer in the media (mostly in reference to the vaccine) influenced how you think about cervical cancer?
- Do you think you will get cervical cancer? Please explain why or why not.

- Have you been identified as being “at-risk” for cervical cancer (i.e. had an “abnormal” Pap smear)? If the answer is yes, please describe this experience, including how this was monitored and/or treated and your recollections/feelings about the experience(s).

Cervical cancer screening & risk prevention:

- If you have had a Pap test, please describe your experiences of Pap smears. Can offer a description of a particular test that stands out in memory or general impressions gathered over the years.
- Why do you think it is important to have Pap smear tests? Please explain why or why not.
- Do you feel there are risks associated with having a Pap smear? Please explain.
- Have you been tested for HPV? Do you think women should be tested for HPV? Please explain why or why not. Is this preferable over a Pap smear? Please explain further.
- Has recent media coverage surrounding the links between HPV and cervical cancer (mostly in reference to the vaccine) influenced your decision to seek or not to seek a Pap smear or HPV test? Please explain.
- What do you think about the HPV vaccine?
- Do you feel there are risks associated with having the HPV vaccine? If yes, please explain.
- What do you think about the provincial government recommendation that grade 8 girls be vaccinated free of charge through the public school system?
- Do you think the vaccination policy should be opened up to provide vaccinations free of charge for young women/women in other age groups or boys/young men? Please explain why or why not.
- How did you reach the decision to have the HPV vaccination? What resources did you draw upon in making your decision?

Other areas of interest & bringing interview to a close:

- Are there other topics you would like to talk about? Are there questions you think should be included in this interview?
- If you have any questions, concerns or additional information to add after this interview, please feel free to contact me by e-mail at mwywest@yorku.ca.

Appendix F – Interviewee Profiles

Patients

Pseudonyms have been assigned, identifying information has been altered and all patients live in the Greater Toronto Area

1) Monica, 28, nurse, single (but, in on and off-again relationship with male), lives in large urban centre.
2) Rebecca, 40, manager of a retail store, married with one child, lives in large urban centre
3) Jennifer, 40, HR senior manager, single, lives in large urban centre
4) Kathryn, 32, urban planner, single, lives in large urban centre
5) Maggie, 26, physiotherapist, single, lives in large urban centre
6) Naomi, 28, MBA student, in a new heterosexual relationship, lives in large urban centre
7) Zoe, 30, high school teacher, married, lives in large urban centre
8) Jill, 40, sales rep., single, lives in large urban centre
9) Christine, 28, paralegal, single, lives in suburbs
10) Allison, 40, chef, in a relationship, lives in the country
11) Laurie, 35, graphic artist, in a relationship, lives in suburbs
12) Adrianna, 28, nurse, single, lives in a large urban centre
13) Emily, 29, accountant, single, lives in large urban centre
14) Megan, 27, freelance writer and editor, engaged, lives in large urban centre
15) Sylvia, 34, dietician, single, lives in large urban centre
16) Liz, 26, occupational therapist, engaged to be married, lives in the suburbs

17) Heather, 26, advertising account executive, in a long-term relationship, lives in a large urban centre
18) Sara, 24, graduate student, single, lives in large urban centre
19) Nicole, 25, journalist, in a casual relationship, lives in large urban centre
20) Alicia, 37, social worker, single, lives in large urban centre

Mothers

Pseudonyms have been assigned and identifying information has been altered.

1) Karen, 44, married with three kids, engineer, lives in a suburb of Toronto
2) Alexandra, 38, married with two kids, entrepreneur, lives in the countryside outside of Toronto
3) Margot, 38, stay-at-home mother, married, five kids, lives in Toronto
4) Serena, 45, journalist, married with three kids, lives in Toronto
5) Gabrielle, 39, academic, married with three children, lives in Toronto
6) Carole, 41, stay-at-home mother, married with two children, lives in suburb outside Toronto
7) Giuliana, 36, stay-at-home mother with part-time business from home, married with three children, lives in Toronto
8) Carmen, 39, college professor, single, one daughter, lives in Toronto
9) Andrea, 43, entrepreneur, married, mother of three, lives in suburbs of Toronto
10) Mary, 36, public relations executive, married, mother of two, lives in Toronto
11) Heather, 40, physiotherapist, married, mother of four, lives in Toronto
12) Colleen, 36, runs home-based business, married, mother of one, lives in Toronto

13) Kathy, 48, lawyer, married, mother of three daughters and a son, lives in Toronto
14) Rachel, 39, librarian, single, mother of 1, lives in Toronto
15) Tracey, 41, high-school teacher, mother of one, lives in Toronto
16) Bronwyn, 40, freelance journalist and editor, married, mother to three children, lives in Toronto
17) Annabelle, 46, nurse, married, mom of two, lives in suburbs of Toronto
18) Joanne, 38, journalist, married, mom of three, lives in Toronto
19) Camille, 38, stay-at-home mother, married, four children, lives in suburbs of Toronto
20) Fiona, 40, policy analyst with provincial government, single, mom of two, lives in Toronto

Students

Pseudonyms have been assigned and identifying information has been altered.

1) Ellen, 26, nursing student, single, from Kingston but lives in Ottawa during the academic year
2) Sonia, 24, nursing student, single, lives in Toronto
3) Marie-Josee, 28, graduate student in the life sciences, single, lives in Ottawa
4) Kim, 26, master's student in history, married, lives in Kingston
5) Sam, 22, kinesiology undergraduate student, in a relationship, lives in Toronto
6) Brittany, 22, physiotherapy student, in a relationship, lives in London, Ontario
7) Sydney, 22, nursing student, engaged, lives in Peterborough
8) Jamie, 28, medical student, in a long-term relationship, lives in Ottawa

9) Madeleine, 23, anthropology undergraduate student, lives with partner in Ottawa
10) Stacie, 20, women’s studies undergraduate major, single, lives in a suburb outside of Toronto
11) Morgan, 22, French literature undergraduate major, single, lives in Toronto
12) Amber, 26, first year law student, single, from North Bay, but lives in Toronto during academic year
13) Emily, 22, master’s student in environmental studies, in a relationship, from Sarnia, but lives in Toronto during academic year
14) Sylvana, 27, master’s student in public health, engaged, from Slovakia, but is Canadian permanent resident and lives in Toronto
15) Molly, 21, biology major, in a relationship, international student from Barbados, lives in Toronto for academic year
16) Sadie, 23, mater’s student in public health, single, lives in Toronto
17) Tovah, 27, master’s student in nursing, in a relationship, from London, Ontario, but lives in Toronto during school year.
18) Stephanie, 24, kinesiology undergraduate major, in a relationship, lives in Toronto
19) Trish, 22, psychology major, in a relationship, lives in Toronto for academic year, but is from Arnprior, Ontario
20) Katie, 24, Bachelor of Education candidate, singles, lives in Toronto
21) Jasmine, 21, sociology undergraduate major, lives in Toronto
22) Jacquie, 28, PhD student in women’s studies, married, lives in Toronto

23) Lison, 27, master’s of social work student, single, is from France, but has Canadian permanent residency and lives in Toronto

24) Maya, 27, master’s in nursing student, single, is from Nova Scotia, but lives in Toronto permanently now

Appendix G – Mother and Student Consent Form

Individual Informed Consent Form for In-Depth Interviews -

CONSENT TO PARTICIPATE

I agree to participate in a research project called "Risk, biological citizenship & gender: an ethnographic exploration of HPV and cervical cancer prevention policy in Ontario", conducted by Michelle Wyndham-West, a doctoral candidate in anthropology at York University. The information will be used in the writing of Michelle Wyndham-West's dissertation. I understand that information I provide will be audiotaped and will be kept in the strictest of confidence. It is anticipated interviews will take approximately 45 minutes to an hour to complete. I also understand that I may choose not to respond to questions and may withdraw from this interview any time in the process. I understand that any information that I give will not be attributed to me by name and that every effort will be made to protect the confidentiality of the information I provide. Confidentiality will be provided to the fullest extent possible by law. I understand any notes or audio taping of my interview will be kept in locked storage and destroyed once the study is complete. This study proposes minimal risk to participants as the study focuses upon the collection of individual narratives and will not affect access to medical services regarding cervical cancer prevention. Your decision not to volunteer will not influence the nature of your relationship with York University either now, or in the future. In the event you withdraw from the study all associated data collected will be immediately destroyed wherever possible.

If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Naomi Adelson, Department of Social Anthropology, by telephone at (416) 736-2100 or by e-mail at nadelson@yorku.ca. The researcher can also be reached by e-mail at mwywest@yorku.ca. Additional information regarding the research project can be found at http://www.yorku.ca/gradanth/students.html. This research has been reviewed by the Human Participants Review Subcommittee (York University's Ethics Review Board) and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Manager, Research Ethics, York University, 309 York Lanes, telephone 416-736-2100 ext. 55914.

I *(fill in your name here)*, consent to participate in "Risk, biological citizenship & gender: an ethnographic exploration of HPV and cervical cancer prevention policy in Ontario" conducted by Michelle Wyndham-West. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

____________________ Date_________________________
Participant

______________________ Date__________________________

Principal Investigator

Appendix H – York University Ethics Amendment Application to Interview Students

REQUEST FOR APPROVAL of an AMENDMENT to an APPROVED PROTOCOL

Who should complete this form: Researchers requesting approval of a change to an approved ethics protocol

Instructions: **Please complete this form and submit it to,**
Alison Collins-Mrakas, Manager,
Office of Research Ethics,
Room 309 York Lanes
Or, electronically to: acollins@yorku.ca

Principal Investigator: Michelle Wyndham-West

Project Title: Enacting biological citizenship through risk and gender: an ethnographic exploration of HPV and cervical cancer prevention policy in Ontario

Certificate #: STU 2009 - 103

Which element(s) of the protocol require(s) amendment (i.e. risks, participant pool, recruitment method etc.)?

Participant pool

Please describe the proposed amendment:

I would like to add a participant pool of 20 York University students (female only and 16 years of age or older) to my current research. If permission is granted, I will recruit said participants by affixing recruitment posters around the university and putting ads in the student newspaper.

Does this represent a substantive change to the approved protocol? Why or why not?

This does not represent a substantive change of the approved protocol. All parameters of the approved protocol will stay the same and the interview schedule provided on pages 68 to 69 (Appendix B) in the protocol will be used for interviewing York University students. The student interviews will augment the current research that is underway.

NOTE:

(i.) If the changes ARE substantive, please note that a full committee review is required. Please re-submit a revised HPRC protocol to the HPRC/Manager Research Ethics at your earliest convenience.

(ii.) If there are changes in your Informed Consent Form, please append the revised copy.

_____M. Wyndham-West___________ ___Dec. 1/09__________________

P.I. Signature Date

COMMITTEE REVIEW (To be completed by Manager, Research Ethics and/or HPRC member(s) only)

Comments:

____

____

____

____

____

____

____

____

Recommendation:________________________________

Reviewed by: ______________________ ______________________

Title **Signature**

____

Date

Appendix I – York University Ethics Extension

YORK
UNIVERSITÉ
UNIVERSITY

Memo

Certificate #: STU 2009 - 103

Renewal Approved: 07/19/10

Office of research ethics (ore)
Fifth Floor, YRT

4700 Keele St.
Toronto ON
Canada M3J 1P3
Tel 416 736 5914
Fax 416 736 5837
www.research.yorku.ca

To: Michelle Wyndham-West, Department of Social Anthropology
mwywest@yorku.ca

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics
(on behalf of Daphne Winland, Chair, Human Participants Review Committee)

Date: **Monday July 19th, 2010**

Re: Ethics Approval

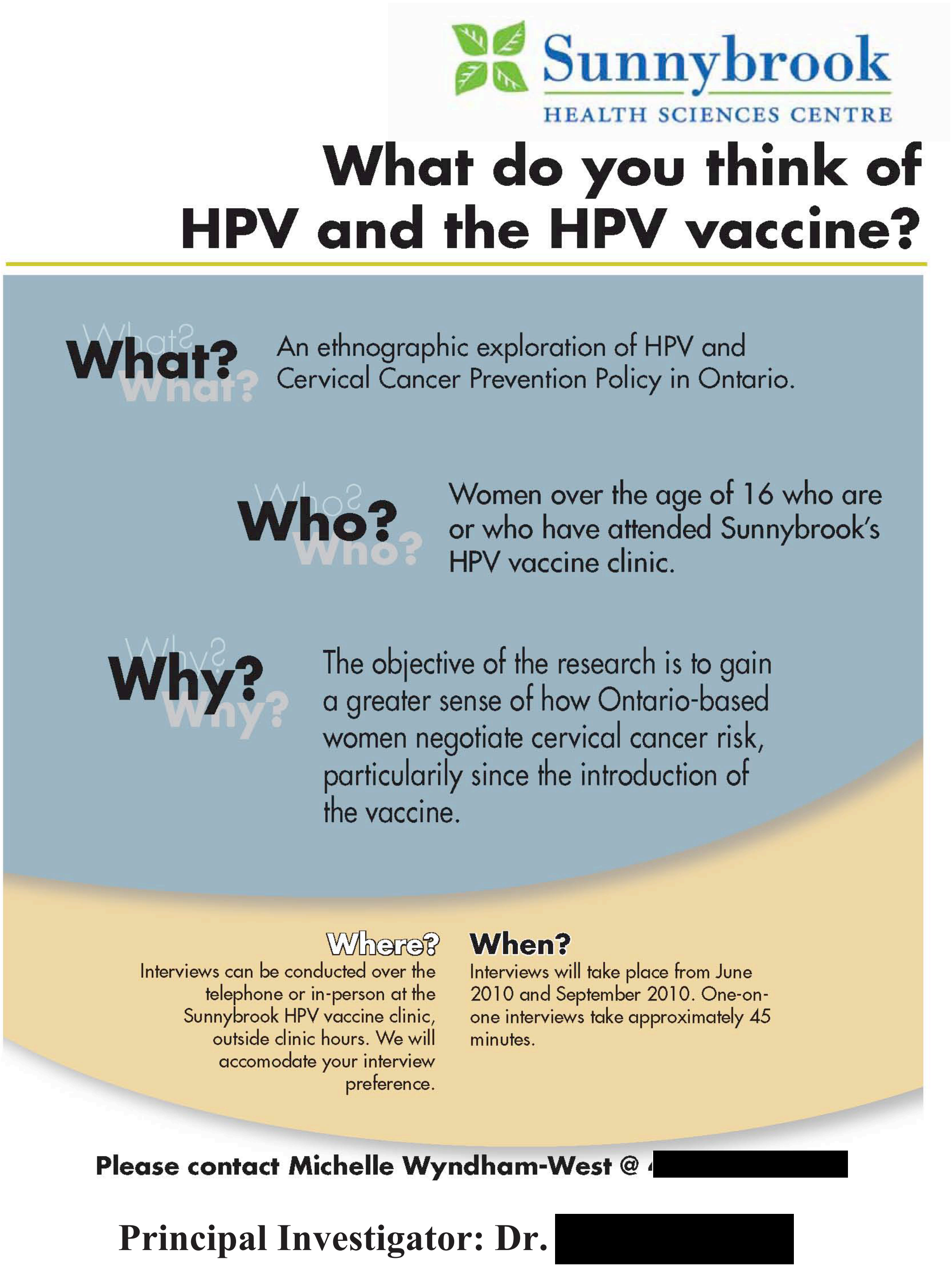
Enacting Biological Citizenship through Risk and Gender: An Ethnographic Exploration of HPV and Cervical Cancer Prevention Policy in Ontario

I am writing to inform you that, with respect to the above-noted project, the committee notes that, as there are no substantive changes to either the methodology employed or the risks to participants in and/or any other aspect of the research project, a renewal of approval re the above project is granted.

Should you have any questions, please feel free to contact me at: 416-736-5914 or via email at: acollins@yorku.ca.

Yours sincerely,
Alison M. Collins-Mrakas M.Sc., LLM
Sr. Manager & Policy Advisor, Research Ethics

Appendix J – Sunnybrook Recruitment Poster



Sunnybrook
HEALTH SCIENCES CENTRE

What do you think of HPV and the HPV vaccine?

What? An ethnographic exploration of HPV and Cervical Cancer Prevention Policy in Ontario.

Who? Women over the age of 16 who are or who have attended Sunnybrook's HPV vaccine clinic.

Why? The objective of the research is to gain a greater sense of how Ontario-based women negotiate cervical cancer risk, particularily since the introduction of the vaccine.

Where?
Interviews can be conducted over the telephone or in-person at the Sunnybrook HPV vaccine clinic, outside clinic hours. We will accomodate your interview preference.

When?
Interviews will take place from June 2010 and September 2010. One-on-one interviews take approximately 45 minutes.

Please contact Michelle Wyndham-West @ [redacted]

Principal Investigator: Dr. [redacted]

Appendix K – Sunnybrook Recruitment Letter

Recruitment Letter for Clients of Sunnybrook's HPV Vaccine Clinic –

Dear Sunnybrook Clinic Attendee:

Michelle Wyndham-West is a PhD student at York University and she is currently researching Ontario's cervical cancer prevention policy, including the HPV vaccine. She is investigating how women negotiate cervical cancer risk for themselves and, particularly, in respect to the HPV vaccine. This project is being carried out in conjunction with Sunnyb[redacted]ciences Centre and Dr. is serving as the Principal investigator of the research project.

If you are interested in participating in the research project, please find attached a consent form to be signed. If you have questions about the research, please feel free to contact Michelle Wyndham-West by e-mail at mwywest@yorku.ca. Additional information regarding the research project can be found at http://www.yorku.ca/gradanth/students.html. This research has been reviewed by the Human Participants Review Subcommittee (York University's Ethics Review Board) and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Thanks so much for your time and consideration.

Appendix L - Sunnybrook Consent Form

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Full Study Title: An ethnographic exploration of HPV and Cervical Cancer Prevention Policy in Ontario.

Principal Investigator: **Dr. [redacted] Women and Babies, Sunnybrook Health Sciences Centre. Telephone number: 416-[redacted].**

Sponsor: **This study is not being funded. Michelle Wyndham-West, a PhD student at York University, who is working with Dr. [redacted], is receiving a scholarship from the Canadian Institutes of Health Research.**

INFORMED CONSENT

You are being asked to consider participating in a research study. A research study is a way of gathering information on a treatment, procedure or medical device or to answer a question about something that is not well understood. This form explains the purpose of this research study, provides information about the study procedures, possible risks and benefits, and the rights of participants.

Please read this form carefully and ask any questions you may have. You may take as much time as you wish to decide whether or not to participate. Please ask the nurse at the HPV clinic to clarify anything you do not understand or would like to know more about. Make sure all your questions are answered to your satisfaction before deciding whether to participate in this research study.

INTRODUCTION

You are being asked to consider participating in this study because you have or are attending Sunnybrook's HPV vaccine clinic.

The objective of the research is to gain a greater sense of how Ontario women think about cervical cancer risk, particularly since the introduction of the HPV vaccine. We are trying to understand how increasing HPV awareness and the HPV vaccine is influencing cervical cancer risk prevention, such as practices like Pap tests. Existing research does not explore in detail how women think about HPV and the HPV vaccination. This narrative-based research project, meaning women will be interviewed one-on-one regarding their thoughts on HPV, the HPV vaccine and general cervical cancer prevention, begins to fill that gap.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to record women's thoughts and experiences in regard to cervical cancer risk since the introduction of the HPV vaccine. This will be done by holding one-on-one interviews with women who are attending or who have attended Sunnybrook's HPV clinic.

WHAT WILL HAPPEN DURING THIS STUDY?

If an HPV clinic attendee is interested in taking part in the research study, the participant will fill out the informed consent form with the HPV vaccine clinic nurse. Once the informed consent form is complete, Michelle Wyndham-West will arrange a one-on-one interview at your convenience. The interview will be held either over the telephone or in person. Interviews will be about 45 minutes in length and will be recorded via audiotape. Interviews will cover participant's views and experiences regarding: (1) risk and cervical cancer; (2) HPV awareness; (3) cervical cancer screening, such as Pap tests; and (4) how you came to the decision to have the HPV vaccine.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?

About 20 to 25 people will participate in one-on-one interviews. The study is expected to take five months to finish and the results should be known in the fall of 2011.

WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?

If you decide to participate in this study you will be asked to do the following:

Participants will be asked to take part in one interview, which is expected to take approximately 45 minutes. Interviews can be conducted over the telephone or in-person at the Sunnybrook HPV vaccine clinic outside regular clinic hours. Interviews will be scheduled at a time and date,which is convenient for you. Participants may choose not to answer a question or a series of questions during the interview. Participants may end the interview at any point throughout the interview.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

There are no medical risks to you from participating in this research study, but taking part in this study may make you feel uncomfortable. You may refuse to answer questions or stop the interview at any time if you are uncomfortable.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

There are no medical benefits to you from taking part in this research study.

CAN PARTICIPATION IN THIS STUDY END EARLY?

The investigator may decide to remove you from this study without your consent for not keeping a pre-arranged interview appointment. You can also choose to end your participation at any time.

WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?

Participation in this study will not involve any additional costs to you.

ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to participate in this study.

DOES THE INVESTIGATOR HAVE ANY CONFLICTS OF INTEREST?

There are no conflicts of interest to declare related to this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

All participants in a research study have the following rights:

1. **You have the right to have this form and all information concerning this study explained to you and if you wish translated into your preferred language.**

2. Participating in this study is your choice (voluntary). You have the right to choose not to participate, or to stop participating in this study at any time without having to provide a reason. If you choose to withdraw, your choice will not have any effect on your relationship with Sunnybrook Health Sciences Centre or its HPV clinic.

3. **You have the right to receive all significant information that could help you make a decision about participating in this study. You also have the right to**

ask questions about this study and your rights as a research participant, and to have them answered to your satisfaction, before you make any decision. You also have the right to ask questions and to receive answers throughout this study. If you have any questions about this study you may contact the person in charge of this study: Dr. [redacted]**, tel.: (416)** [redacted]**. If you have questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may call** Dr. Philip C. Hébert, Chair of the Sunnybrook Research Ethics Board at (416) 480-4276.

4. You have the right to have any information about you that is collected, used or disclosed for this research study to be handled in a confidential manner.

If you decide to participate in this study, the investigator(s) and study staff will look at your personal health information and collect only the information they need for this study. “Personal health information” is health information about you that could identify you because it includes information such as your;

- name,
- address,
- telephone number,
- date of birth,
- new and existing medical records, or
- the types, dates and results of various tests and procedures.

The following people may come to the hospital to look at your personal health information to check that the information collected for the study is correct and to make sure the study followed the required laws and guidelines:

- Representatives of the Sunnybrook Research Ethics Board, a group of people who oversee the ethical conduct of research studies at Sunnybrook.

Access to your personal health information will take place under the supervision of the Principal Investigator.

In addition, any study data about you that is sent outside of the hospital will have a code and will not contain your name or address, or any information that directly identifies you. “Study data" is information about you that is collected for the research study, but that does not directly identify you.

Study data that is sent outside of the hospital will be used for the research purposes explained in this consent form.

The investigator, study staff and the other people listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

When the results of this study are published, your identity will not be disclosed.

The Principal Investigator will keep any personal information about you in a secure and confidential location for five years and then destroyed as required by Sunnybrook policy.

5. By signing this consent form, you do not give up any of your legal rights.

6. You have the right to receive a copy of this signed and dated informed consent form before participating in this study.

7. You have the right to be told about any new information that might reasonably affect your willingness to continue to participate in this study as soon as the information becomes available to the study staff.

8. You have the right to access, review and request changes to your personal health information.

9. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please provide your name, address and telephone number to Michelle Wyndham-West, PhD Student, York University, tel.: [redacted].

DOCUMENTATION OF INFORMED CONSENT

Full Study Title: An ethnographic exploration of HPV and Cervical Cancer Prevention Policy in Ontario.

Name of Participant: ______________________________________

Participant/Substitute decision-maker

By signing this form, I confirm that:

- This research study has been fully explained to me and all of my questions answered to my satisfaction
- I understand the requirements of participating in this research study
- I have been informed of the risks and benefits, if any, of participating in this research study
- I have been informed of any alternatives to participating in this research study
- I have been informed of the rights of research participants
- I have read each page of this form
- I authorize access to my personal health information and research study data as explained in this form
- I have agreed to participate in this study or agree to allow the person I am responsible for to participate in this study

__________________ __________________ ______________

Name of participant/Substitute decision-maker (print) Signature Date

Person obtaining consent

By signing this form, I confirm that:

- This study and its purpose has been explained to the participant named above
- All questions asked by the participant have been answered
- I will give a copy of this signed and dated document to the participant

__________________ __________________ ______________

Name of Person obtaining consent (print) Signature Date

Statement of Investigator

I acknowledge my responsibility for the care and well being of the above participant, to respect the rights and wishes of the participant as described in this informed consent document, and to conduct this study according to all applicable laws, regulations and guidelines relating to the ethical and legal conduct of research.

____________________ ____________________ _______________

Name of Investigator (print) Signature Date

ASSISTANCE DECLARATION ☐ (check here if not applicable)

The participant/substitute decision-maker was assisted during the consent process as follows:

☐The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant/substitute decision-maker.

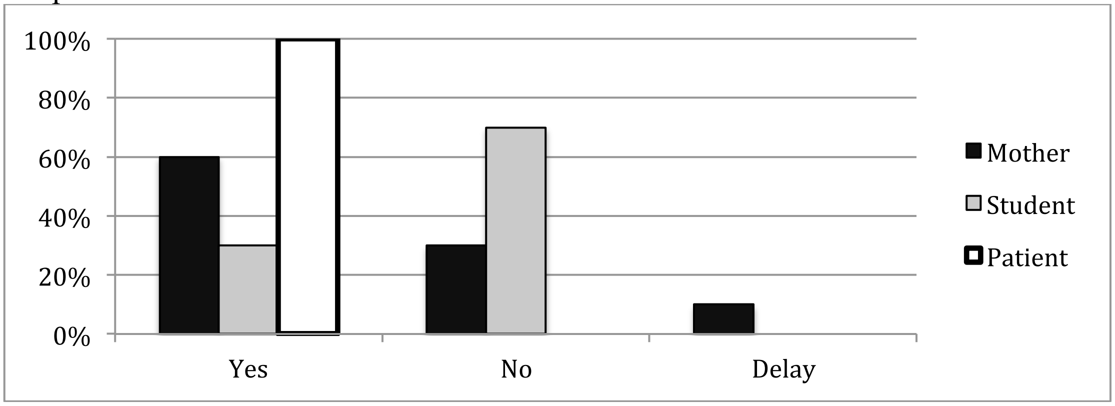
☐The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that they have accurately translated the information for the participant/substitute decision-maker, and believe that that participant/substitute decision-maker has understood the information translated.

____________________ ____________________ _______________

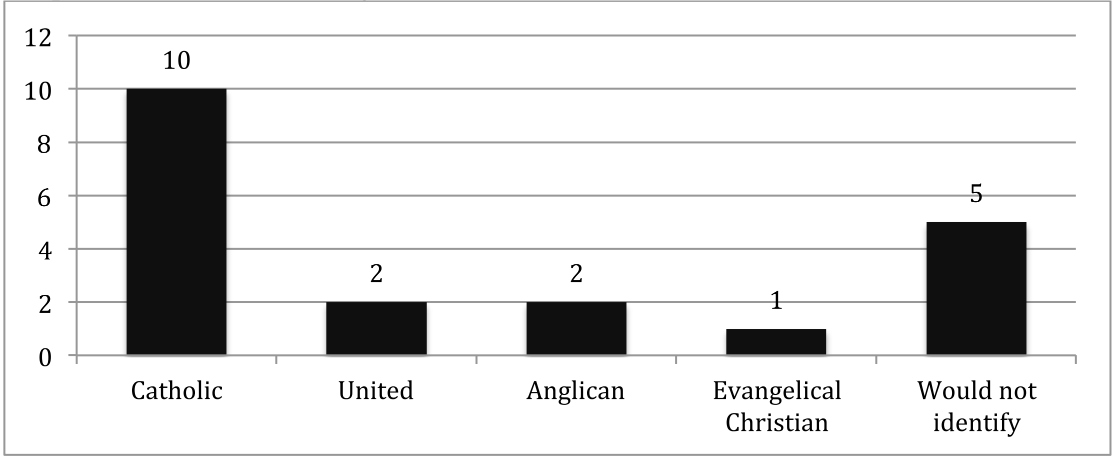
Name of Person Assisting (Print) Signature Date

Appendix M – Interview Data

Graph 1 - Vaccine Decisions



Graph 2 - Mothers and Religion



Graph 3 - Patient Health Insurance