In practice: narrative care & decision-making among pediatric and adolescent health providers

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IN PRACTICE: NARRATIVE CARE & DECISION-MAKING AMONG
PEDIATRIC AND ADOLESCENT HEALTH PROVIDERS

by

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DEDICATION

Dedicated to my grandparents
ACKNOWLEDGEMENTS

My interest in anthropology may have gone unexplored if not for the contributions of my mentors in various departments at Colby College. Their dedication to their respective fields and to their students, both in the classroom and outside of it, continues to inspire how I approach Anthropology and the world.

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And last, but in no way least, I am grateful for each of my families. In your own ways, you have supported and encouraged me from the very beginnings, and nothing would have been possible otherwise.
IN PRACTICE: NARRATIVE CARE & DECISION-MAKING AMONG 
PELLDIATRIC AND ADOLESCENT HEALTH PROVIDERS 

KATIE-ELYSE TURNER

ABSTRACT

This thesis explores the experiences of several pediatric health care providers in the Boston area. It identifies and examines the stories told by providers to discuss their profession, their decision-making processes, and the methods that they use to “know” themselves and their patients through the lens of current topics of interest in pediatrics, including the Human Papillomavirus (HPV) vaccines. Pediatricians, pediatric nurse practitioners, adolescent health providers, and pediatric focused gynecologists were recruited from several private, community-based, and academic medical center practices in the Boston area. This study used several qualitative data collection methods, focusing primarily on the use of semi-structured interviews while including participant and non-participant observations in two distinct clinical settings.
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## Abbreviations

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<tr>
<th>Abbreviation</th>
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<tr>
<td>AANP</td>
<td>American Academy of Nurse Practitioners</td>
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<td>AAP</td>
<td>American Academy of Pediatrics</td>
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<td>AMA</td>
<td>American Medical Association</td>
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<td>ACIP</td>
<td>Advisory Committee on Immunization Practices</td>
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<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
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<td>CME</td>
<td>Continuing Medical Education</td>
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<td>DO</td>
<td>Doctor of Osteopathic Medicine</td>
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<td>EMR</td>
<td>Electronic Medical Record</td>
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<td>FDA</td>
<td>Food and Drug Administration</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<td>HBV</td>
<td>Hepatitis B Vaccine</td>
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<td>HPV</td>
<td>Human Papillomavirus</td>
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<td>IRB</td>
<td>Institutional Review Board</td>
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<td>MA</td>
<td>Medical Assistant</td>
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<td>MD</td>
<td>Medical Doctor</td>
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<td>MDM</td>
<td>Medical Decision Making</td>
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<td>NP</td>
<td>Nurse Practitioner</td>
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<td>PA</td>
<td>Physician’s Assistant</td>
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<td>RN</td>
<td>Registered Nurse</td>
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<td>STD</td>
<td>Sexually Transmitted Disease</td>
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<td>WHO</td>
<td>World Health Organization</td>
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CHAPTER I: Introduction

I heard the jingle as I walked by the television on a Saturday night: “It’s Lil’ Poundcake, the sweetest doll on the block! She has a purse, and hair that grows…” I was confused for a moment until I realized that what I thought to be a 1990s era doll commercial turned out to be a Saturday Night Live (SNL) spoof about a politically controversial vaccine for young girls and women. The young girls and their “Lil’ Poundcake” dolls in this “commercial” were busy selling lemonade, having tea and dance parties, going to school, and playing with friends. The teenage female narrator went on: “Lil’ Poundcake is the first doll approved to administer the human papillomavirus vaccination to girls under ten!” The girls were doing everyday young girl activities while syringes popped out of their dolls’ palms to administer them a dose of the HPV vaccine: “Lil’ Poundcake…the only thing you’re gonna get infected with…is fun!”

My interest in vaccines, and provider presentation of vaccines and vaccination in particular, was piqued in early 2007. While catching up with a good friend from high school, we started talking about the health care options available at our respective undergraduate institutions. She recounted her recent trip to her pediatrician’s office, where she continued to receive primary care while in college. She said that, in addition to all the shots for which she was due, she also received a mysterious one that was presented as a cancer preventing vaccine. I asked some questions, but the discussion fell aside in favor of updating one another on our lives and the adventures of others.

I revisited this conversation the following year as I began to explore my interest in health care delivery and systems as part of a research project. I did some reading, watched commercials, spoke with the medical providers at my disposal, and found myself intensely interested in how this vaccine had been developed and marketed to doctors and patients. This topic would inspire several years’ worth of benign, and some not so benign, conversations and intense media coverage of spheres of influence ranging from neighborhood pediatric offices to national political campaigns.

The “Lil’ Poundcake” spoof was produced in late 2011, and came at the tail end of interest surrounding the development, marketing, and usage of that mysterious vaccine: the Human Papillomavirus (hereinafter, HPV) vaccine. At that time the spoof was produced, this project was in the midst of data collection, and I found my interest in public perceptions of medical products, and the influences of these perceptions, renewed. The video highlighted many of the tensions I had informally observed over the past few years as a patient eligible for this vaccine, and it also affirmed some of the stories and concerns of public perception that I was hearing from pediatricians.

The strength of anthropology is its ability to focus on stories, whether they are life histories, current events, or a simple recounting of one’s daily experiences. Cultural anthropologists place these stories in social, political and economic contexts in order to piece together a more complete picture of local individuals operating within an increasingly global context (Appadurai 1996). The value of this approach lies in its fundamental understanding that stories are able to communicate the nuances of individual experience that are often masked by numbers, statistics, and political rhetoric.
As an emerging medical anthropologist, I chose to focus on stories that are reflective of experiences and social constructs related to health, medicine, systems of healing, and the body in all its iterations. My approach to the world is anthropological in nature, and it is through the lens of medical anthropology in particular that I found the tools to explore my interest in HPV vaccines and the relationships between medical patients and medical providers. This field of interest soon expanded to include the stories that doctors and patients told about their experiences interacting with each other through the lenses of office visits, media knowledge, and their own experiences with pediatric vaccinations.

This thesis is based on stories told by pediatric health care providers in the greater Boston area who were generous with their time and kind enough to share their experiences and perceptions of their practices. These physicians and nurse practitioners shared stories about themselves and their practices. They communicated, both subtly and overtly, the experience of practicing pediatric at a time when their individual expertise and collective medical specialty is under constant scrutiny and questioning from those within and outside of the medical community. This study focuses on decision-making stories as related to the usage of vaccines in pediatric practice; in addition, several other “tools” of the biomedical trade are used as examples to illustrate how learned knowledge and decision-making are used, or not used, in every day practice.

*Study Overview*

This study set out to explore the decision-making processes and contexts related to the HPV vaccine among pediatric health care providers in the Boston area. In addition
to a review of popular media coverage, advertising, and academic literature, the project’s methodology relies on qualitative interviews and participant observation within various types of pediatric practices.

The initial goal of the project was to collect various stories and forms of evidence regarding decision-making processes from pediatric providers. As the study progressed, it became clear that pediatric health care providers use several frames for decision-making and “non-making” within their individual practices. My research participants found my research questions interesting but limited, and found several avenues by which they could expand upon the study’s premise and illuminate other phenomena within their field. Therefore, this study reports and explores the outcome of participant-directed conversations, which are woven together by the study’s overall goal, broader themes of decision knowledge and biomedicine, and my own research influence.

This thesis argues that individual pediatric providers make very few explicit or unguided decisions regarding patient care, and instead choose from and utilize a wide lateral range of pre-determined decisions given the context of a patient care situation. This is not a new phenomenon within medicine, nor, according to my participants, is it one that has gone unexplored at the individual, practice, and specialty levels. Pediatricians and other types of pediatric health providers\(^2\) are painfully aware of the perception that their specialty’s range of decision-making consists of deciding how to treat runny noses and schedule annual vaccinations. The range of decisions available to these providers is more nuanced than they perceive, particularly given the multitude of

\(^2\) Such as nurse practitioners or physician’s assistants.
moving parts related to the structuring of the profession and the stakeholders that they must engage.

At several points during this project, providers mentioned that the “art of medicine” was of equal or greater importance to the “science of medicine,” and that their individual and collective decision-making was a subtle nod to the process of medicine as an evolving “scientific art.” With this in mind, I explore my argument through the processes of pediatric practice: learning to be a pediatrician, theoretically knowing how to be a pediatric provider, actually practicing the “scientific art” of pediatric medicine, and, within each of these, identifying how particular medical products (such as vaccines) are used in clinical practice. To outline each of these processes in further detail, I will use examples highlighted by my participants as well as the aforementioned review of popular media, advertising, and academic literature.

Chapter II outlines the background knowledge necessary to understand the positioning of this study in relation to the current qualitative literature of physician knowledge and practice. There are two parallel modes of inquiry that tie this section together, and these overlap and connect at varying junctures. The first approach is that of medical anthropology. This field explores how individuals approach, perceive, operate within, and are constrained by, medical systems and various conceptions of what health, disease, sickness, and healing mean. The second approach uses biomedicine, the medical system within which my participants operate, to provide a lens on how doctors are trained academically and practically. The overarching purpose of this section is to educate the reader with regards to the historical and current relationship between anthropology and
biomedicine, and how the intersections between these fields have been explored individually and together using both qualitative and quantitative perspectives.

Methodology & Findings (Chapter III) expands on the background section to further delve into how this study’s methods are informed by the reliance on quantitative methods within biomedicine and on qualitative methods within anthropology. I purposely address the data resulting from this study as “findings” rather than “results” as a way of diverting attention from measurable outcomes while empowering the sometimes inconclusive nature of qualitative research studies such as this one. The chapter includes detailed descriptions about methodology development during the initial planning stages as well as how these methods were revised in the field based on shifting resource availability and researcher access. Of particular note within Chapter III is a description of recruitment techniques used to identify potential participants, and a high-level description of the sample. This chapter concludes with a description of the data analysis processes and a brief introduction to the connections between the discrete pieces of data (codes and themes) and the narratives contained within the sources of data (qualitative interviews and participant observation).

Chapter IV analyzes how the processes of learning and maintaining knowledge inform pediatric practitioners’ relationships with patients, other providers, and of the profession of medicine. This chapter argues that knowledge based processes are a vital starting point to understand how pediatric providers come to know their role within the profession of medicine and, more specifically, within the specialty of pediatrics. Beyond the acquisition of medical and practice-based knowledge, I examine how pediatric
practitioners come to “know” their patients and their role in the broader biomedical sphere. Of note in this chapter is a case study of two pediatric primary care nurse practitioners, both of whom occupy a vital role within their practices, but are limited in their practice by regulatory restrictions and guidance. Individual nurse practitioners (NPs) are considered “mid-level providers,” a term fraught with political complications and professional identity crises. I will explore this term, and the liminal space within which NPs operate, as a way of elucidating how a growing group of pediatric primary care providers come to know their various roles.

The fifth chapter explores the second step of “knowing” various pieces of information, namely, the “sharing” of knowledge and resources as a part of the day-to-day practice of pediatric medicine. This chapter argues that, while pediatricians have an evolving knowledge base from which they draw for specific situations, this base mostly consists of pre-determined decisions from which providers choose the most fitting outcome. These decisions indicate that the practice of medicine is not only referential to previous personal and collective experiences of patient health outcomes, but that it is also reliant on previous political or social situations used to inform current responses to similar situations. Outlined in this chapter is one such response: that of pediatricians’ personal and professional reactions to the HPV vaccine controversy and a comparative case study to the Hepatitis B vaccine developed in the early 1980s.

Chapter VI gives an overview of the ways in which the findings of this study are both conclusive and inconclusive, and makes a case for further qualitative study of how pediatric providers frame their personal and professional narratives in relation to their
various practice environments. This chapter will also delve into some of the limitations of this study including, but not limited to, the constraints on providers’ time and the availability of potential participants during the data collection period. To close, this chapter will briefly outline some of the study’s prominent themes not highlighted elsewhere, and argue that there are further connections to other narratives of pediatric practice.
CHAPTER II: Background & Literature Review

Medical anthropology offers a unique approach to the study of biomedical processes and constructs; yet there is reluctance on the part of anthropologists to rely on biomedical terminology or concepts. The purpose of this chapter is to provide an entrée into the relevant biomedical and anthropological terminology, processes, and theoretical approaches used throughout the lifecycle of this study. I focus on the ways that both anthropological theory and biomedical health care informed the development of my research questions, and how the relationship between these fields impacts how pediatric focused health care providers learn, maintain, and apply knowledge in narrative reflections on their individual and collective practices.

This chapter will purposely tack back and forth between anthropological approaches to specific biomedical concepts and the development of specific modes of care used in pediatric practice, with a particular emphasis on vaccines and vaccination practices. My original research questions focused on how pediatric providers came to personal and professional decisions, and I sought to use the HPV vaccines as a lens for understanding these decision-making processes. As my data collection progressed, I found that there were several other approaches used by providers to understand their decisions and their practice environments. I have incorporated pertinent information regarding these examples here, and have used them throughout the study to explicate the ways in which providers understand their practices.

For the purposes of this study, I limit any discussion of the HPV vaccines to Gardasil, which is produced by the New Jersey based pharmaceutical company, Merck &
Co. (hereinafter, Merck). My participants identified Gardasil as the vaccine of choice in their practices and in the United States. GlaxoSmithKline, a UK based pharmaceutical company, produces a similar vaccine known as Cervarix, which targets slightly different strains of HPV and is not widely advertised or used in the United States.

*Identifying the Expert and “Studying Up”*

For individuals credentialed as biomedical practitioners\(^3\), there is an underlying tension related to maintaining one’s professional identity and placement within the professional hierarchy. Doctors (MDs and DOs) are perceived as embodying an advanced understanding of disease processes and as setting the standard for competent medical care. Nurse Practitioners (NPs) or Physician’s Assistants (PAs), both of which occupy a more limited scope of practice and are often supervised by a doctor, are in turn perceived as more competent than Registered Nurses (RNs) or Medical Assistants (MAs). Outlining this professional hierarchy, the work assigned to each type of practitioner, and the influence of the medical “expert,” is crucial for understanding how medical providers learn and share information, and a necessary first step in identifying the practice of medicine as an advanced profession worthy of anthropologists’ attention.

The construct of various levels of the “medical professional” conforms to Abbott’s observation that the application of work to, and division of work within, a

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\(^3\) Due to the varied practitioner “types” within my sample population, I purposely use ambiguous terms such as “clinician,” “provider,” or “practitioner” when discussing groups of differently credentialed medical providers. While each term embodies a distinct approach to and understanding of the role of biomedical professionals in the United States, the fluidity of these terms glosses over the power struggle for professional dominance between those who identify with the medical, or disease based, model (doctors) and those who identify with the nursing, or person based, model (nurse practitioners). I will discuss this theme further in Chapter IV, using a case study exploration of how nurse practitioners construct their professional and clinical identities as parallel to and distinct from doctors.
particular profession tends to follow a fairly standard sequence, which is not dissimilar to the formation of a new profession in general (Abbott 1988). Most simply, Abbott argues that identifying the focus and spectrum of a profession’s work, then developing various levels of jurisdiction over that work, and finally maintaining professional controls to avoid or manage competition for jurisdiction are the primary activities for maintaining an expert knowledge base and sustaining a profession. This particular usage of Abbott’s theories assumes the identification of medicine as a profession, and does not focus on the process by which the field came to occupy this designation. Rather, the focus here is on the jockeying that occurs when new controls are developed to regulate the competition for acquisition of the knowledge that falls within medicine’s professional purview.

Medicine’s professional hierarchy is not only restricted to internal perceptions of medical practitioners, but also extends to the placement of medical professionals in the realm of highly valued providers of a specialized service within the more mainstream realm of general understanding of medical practice. Individuals and groups look to medical professionals for advice on a range of issues beyond those that can be identified as purely scientific in nature; the advanced technical knowledge and social training required to provide “competent” medical care in the United States places doctors, and, to a lesser extent, nurses and advanced practice clinicians, in roles of power. Understanding the dynamics of this professional power, and why the medical profession is worthy of anthropological attention, is the starting point for this discussion.

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4 See Gardiner Harris’ October 1, 2011 article in the New York Times for a public discussion of the professional tensions associated with the expanding credentials of non-physician providers.
While the profession of medicine has been working to identify its work and stratify that work to accommodate the growing demands on the field, a concurrent process has been taking place. Doctors and nurses who once provided care and counsel have become “providers” of medical expertise to patient healthcare “consumers” (Hartzband and Groopman 2011), and the practice of medicine has become the business of medicine. This shift toward identifying medical care as a capitalist mode of business has garnered attention from doctors, patients, and governments alike as each attempt to understand how medicine works, and, ultimately whether the “doctor as expert” model can be more powerful than the “medicine as business” model.

The profession of medicine, and individual medical professionals, occupy a position of power within the United States, within the realms of both scientific expertise and capitalist structures. But why study medical professionals, and pediatric professionals in particular, from an anthropological perspective? In “traditional” anthropological work, the anthropologist ingratiates herself in an exotic land or situation where, as an outsider, she maintains both power over her subjects as well as some sense of separation from the events surrounding her self. In calling for anthropologists to “study up” economic and corporate structures, Laura Nader (1992) asked, “what if, in reinventing anthropology, anthropologists were to study the colonizers rather than the colonized, the culture of power rather than the culture of the powerless, the culture of affluence rather than the culture of poverty?” It is this approach, of studying “the culture of power” and of identifying the obstacles to studying cultures of capitalist production, from which this study takes its theoretical and methodological leads.
Biomedicine in Perspective

To fully comprehend the construction of an individual medical professional, one must first explore the theoretical underpinnings that define biomedicine as significant cultural system in and of itself. Anthropology approaches biomedicine as a distinct system that operates outside of, but parallel to, individual understandings of health and the practice of health care. However, we must make the distinction between studying a system, such as biomedicine or the practice of health care in the United States, and developing an understanding of that system’s function. There are several assumptions built into the practice of, and belief in, biomedicine, including the dichotomy between body and mind, the universality of disease processes, and illness “as a ‘natural’ occurrence” (Hahn and Kleinman 1983, 312). The conclusion here, however, is that we not shy away from studying the “exotics at home” (di Leonardo 1998), and instead explore methods of how to study this system. A study of biomedicine, therefore, seeks to understand how the connection between global systems of healthcare and individual, local understandings of healthcare and the individual body contribute to the dominance of biomedical culture in the U.S.

Relying on previous fieldwork experiences, Margaret Lock and Vinh-Kim Nguyen have written extensively that biomedicine and biomedical technologies, such as vaccines, have not only exacerbated global health inequalities, but have also contributed to diminished reflexivity in the practice of medicine (2010). Relevant to this particular study is Lock and Nguyen’s understanding of bodies operating in a local context and interpreting biomedicine within that locality, rather than the body as a universal site of illness and disease and biomedicine as the hegemonic “cure.”
As previously intimated, part of this dominance is the construction of biomedical and professional power located within and applied to clinical practices or locations, medical schools, and medical professionals. In discussing strategies for “making visible the culture of biomedicine,” Lorna Rhodes suggests that “attending to the life worlds…and daily practice of clinicians is [one strategy] revealing of biomedicine’s theoretical and pragmatic foundations” (1996: 167). And in an introduction to a special issue of Medical Anthropology Quarterly focused on clinical reasoning and realities of illnesses, Hunt and Mattingly identify that “studies in clinical settings of the myriad forms and faces of clinical practice allow examination of the multiple forms of rationality that inform both the healer and patient” (1998, 268). The grey areas here, to bring together Hunt and Mattingly with Rhodes, are the daily practices that pervade the culture of biomedicine, and approaching this “how” via the individual clinician’s experience is one of the driving forces behind this study.

Theories of Decision Making
This study originally asked participants to reflect on their decision-making and reasoning processes in the context of vaccination, among other topics. As previously mentioned, one of the common themes that links the various threads of this project is that of clinical reasoning in the face of biomedical and biotechnical assumptions about the individual body. Reasoning, rationality, and decision-making studies traditionally stem from the fields of psychology and sociology in the form of observational data collection and quantitative analysis. There are however, some details of clinical reasoning and decision-making that can be teased out using anthropological theories and methods. I will
first discuss some of the more “traditional” theories of rationality, and then discuss how the field of anthropology has taken these theories and expanded them to accommodate the processes of applying cultural meaning to decision-making in clinical practice.

The field of decision psychology offers fairly straightforward tools for exploring how individuals evaluate information and uncertainty to formulate opinions or decisions about one’s behavior. While many of these have been set aside in favor of a more nuanced approach to behavior studies, a brief overview of two more well-known models of behavior change will inform our understanding of the resources at hand for physicians and other medical professionals when weighing decisions for and with patients.

The health belief model (Rosenstock 1974) is a kind of cost-benefit analysis used to encourage individuals to make changes to their health based on identifying perceived benefits to each change. This model assumes that the “weighing” occurs in a vacuum free of social and environmental influences, and that there is a direct causal link between one’s intention to make a decision or change and their actual behavior. A somewhat more mathematical approach to decision making regarding individual behavior is the theory of reasoned action (Fishbein & Ajzen 1975), which is a similar balancing act between identifying one’s intention or decision regarding a potential outcomes against subjective norms, or what other people think of one’s yet unchanged behavior. While both of these models focus on individual decisions or behaviors, the theory of reasoned action acknowledges that decision-making does not occur in a vacuum, but is subject to cultural and environmental influences.
Within the education and practice of medicine, medical decision making (MDM) “encompasses both individual-level (or ‘clinical’) decision-making and societal-level (‘policy’) decision making” (Schwartz 2011, 69). The education and practice of clinical decision making is focused on how physicians and clinicians deal with the uncertainty that is present when dealing with unknown or unforeseeable outcomes, whereas policy decision making seeks to provide guidance to individual physicians based on aggregated data of health benefits or outcomes.

Connecting these behavioral approaches to patient-specific medical decisions is, however, a different task entirely. Evidence based medicine provides an interesting starting point for connecting health decision behavior models, such as the health belief model, to the practice of using information to make medical decisions in the face of uncertainty. An editorial in the British Medical Journal sought to clear up confusion about the definition of evidence based medicine, and defined it as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients… the practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research” (Sackett et al. 1996). At its most basic level, then, evidence based medicine attempts to form a linear decision-making bridge for physicians by incorporating clinical knowledge, their understanding of a patient’s medical choices, and the research relevant to a particular clinical question. It is a resource ultimately used to inform “patient choice” and clinical decisions.

5 For ease of use, I will refer to each type as clinical decision making and policy decision making.
In a short ethnographic piece about how primary care practitioners arrive at decisions, John Gabbay and Andrée le May set out to explore the use of research and existing evidence in medical decisions at two general practice locations in England. The goal of their study was to “study explicitly the ways in which primary care practitioners – general practitioners (GPs) and practice nurses – use evidence in their day to day decisions about the management of patients.” They found that, despite the multitude of academic resources and professional guidelines available to them within their practice, most practitioners relied on “their professional networks among other doctors” which the authors term “‘mindlines,’ collectively reinforced, internalized tacit guidelines, which were informed by brief reading, but mainly by their interactions with each other and with opinion leaders, patients, and pharmaceutical representatives” (2004: 3). The authors conclude that, for these practices, medical decision making and reasoning is not based on formal guidelines, but on the day to day knowledge used within their practices.

The construction and maintenance of clinical knowledge via physician-to-physician narrative sharing calls into question medical decision-making as a whole and evidence based medicine in particular – how can these models, which incorporate understandings of clinical processes at a population level, be useful if physicians don’t incorporate them into their practice? In a commentary piece highlighting several arguments about decision-making and reasoning in clinical practices, anthropologist Carole Browner makes the astute observation that the subjects of reasoning and “medical ‘choice’… [have attracted] far less attention outside the United States” and that “our fascination may be due to the peculiarly American preoccupation with the illusion that
we control our destiny” (1998: 356). Understanding this “illusion of control” is where anthropological approaches to reasoning can help tease out the relationship between policy decisions or research findings (both of which are used to inform evidence based medicine) and the impact of everyday medical interactions between patients and clinicians. Chapter V will discuss this theme further.

*The HPV Vaccine: History & Physician Acceptance*

Until now I have focused on medical practitioners in general, supported by somewhat broad theories of medical and anthropological reasoning and decision-making. In evaluating the presence of the HPV vaccines in the medical products market and as part of the pediatrician’s vaccine schedule, most studies have focused on patient acceptance of the vaccine and vaccine decision making methods within families or certain patient groups. Researchers have only recently taken a step back and began to think about the intermediary processes of provider decision making and acceptance as barriers to or influences on patient acceptance. Using the development of the HPV vaccines as a frame of reference, this section will first focus on understanding “policy” level approaches to, and acceptance of, the HPV vaccine, and then shift to medical profession’s responses.

To fully understand the context within which the HPV vaccines were developed, one must first understand the public health significance of HPV as a disease. HPV was linked to animal cancers in the 1930s, and to lesions resulting from genital warts in the mid-1950s; the 1980s saw researchers isolate HPV’s genetic materials and begin to make the connection between certain strains of HPV and cancers (Wailoo et al. 2010, xxi).
According to the World Health Organization (WHO 2013), there are more than 100 currently known strains of HPV, many of which are benign; HPV infection is the most common sexually transmitted disease in the United States with 6.2 million new infections occurring annually (Hutchinson and Klein 2008, 2105). Thirteen HPV strains, however, are considered “high risk,” and it is these strains that can cause several types of cancer and genital warts (2013) in both men and women.

Prior to 2006, Papanicolaou screening (also called a Pap smear or Pap test) and HPV specific testing were the primary modes of identifying “abnormal” cervical cells, which indicate infection. These tests, however, only offer a reactive confirmation of the presence of disease; the establishment of a causal link between HPV strains 16 and 18 and genital neoplasms (Koutsky 1997) sparked development of a prophylactic vaccine to address the prevalence of HPV at a population level (Barr and Sings 2008).

In June 2006, the U.S. Food and Drug Administration (FDA) approved Merck’s quadrivalent (protective against four strains) HPV vaccine, Gardasil, for administration to girls ages 9 – 26 (U.S. Department of Health and Human Services 2007), and subsequently approved GlaxoSmithKline’s bivalent (protective against two strains) HPV vaccine in October 2009 (U.S. Department of Health and Human Services 2010).

Since the mid-2000s, several studies have explored pediatric health care provider attitudes and vaccination practices as related to adolescent immunizations, many specific to the new HPV vaccine. Overall, the studies discussed below indicate a high level of

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6 I have restricted this discussion to literature specific to, or including as part of a larger sample, pediatric providers given their prevalence in my own sample and their role as the primary provider of immunizations for Gardasil’s targeted population. For discussion of attitudes and acceptance of the HPV vaccines among Obstetrician-gynecologists, see Leddy et al. 2009; for same discussion specific to Family Physicians, see Riedesel et al. 2005.
vaccine acceptance and “intention to administer” (Kahn et al. 2005) among various physician samples in the United States.

An early survey exploration of pediatrician knowledge and attitudes regarding the licensure of Gardasil (Daley et al. 2006) revealed that a significant portion of a national sample would recommend HPV vaccination in older adolescent females, with slightly less than half the responding sample indicating that they would recommend vaccination in younger (10- to 12-year-old) females. Despite stated concerns about parental vaccine acceptance and financial barriers, pediatrician respondents to this study were in favor of recommending the vaccine if it was part of new immunization recommendations: “respondents who believed that other new adolescent immunization recommendations (e.g., meningococcal, pertussis) would facilitate human papillomavirus vaccine implementation were more likely to intend to recommend the vaccine.” The providers in this study foresaw that the multitude of changes to the adolescent vaccine schedule would aid in vaccine uptake among parents and adolescents.

The providers sampled for a study in 2005, however, had a different understanding of the outcomes related to implementation of that same updated adolescent immunization schedule. The authors found that:

providers indicated that parents were exhibiting ‘vaccine fatigue’ due to an increasing number of vaccines that are recommended. Targeting vaccines to adolescents is a relatively new phenomenon and it is possible that physicians were, in part, projecting their own fatigue. Between 2005 and 2006, the ACIP made an unprecedented seven new recommendations to the childhood and adolescent vaccination schedule…both families and health care professionals may exhibit ‘vaccine fatigue’ due to so many changes and challenges in such a short period of time. (Humiston et al. 2009, 125).
This particular finding helps tie together the policy level decisions and changes that impact the daily practice-based decisions of individual pediatric providers. In interactions with both patients and their parents, it seems that rapidly changing immunization recommendations could impact the physician’s intention to advocate for or administer “optional” vaccines, or those not mandated for school attendance, such as Gardasil.

Several studies have shown that pediatricians play a crucial role in relaying information specific to the HPV vaccines, and that there are common strategies employed in primary care to address perceived and real barriers to vaccination (see McCave 2010 and Tissot et al. 2007). However, there is little research to date regarding physician specific barriers to administering the HPV vaccine. One identified barrier to vaccination includes pediatricians’ distinct approaches to older and younger adolescents, and that, among one sample, “personal reluctance to recommend vaccination to young adolescents and their parents may be linked to a number of clinician beliefs and attitudes. These clinicians may perceive young adolescents to be at low risk for HPV infection or may be hesitant to discuss issues related to sexuality with preadolescents” (Kahn et al. 2005). In 2010, Daley and colleagues highlighted a continued literature gap regarding physician’s professional and personal perceptions of the vaccines and how these perceptions influence knowledge sharing with patients. It is this knowledge gap that inspired my original research questions and this study.

Overall, this chapter constructs the baseline of knowledge needed to understand how this study fits into the intellectual context of anthropology and the field and practice of Western medicine. The next chapter explores the various methodologies used within
this study, as well as some initial findings related to the sample population and data analysis processes. It will continue this chapter’s focus on the intersection between anthropology and biomedicine, but within the context of initial study development and eventual execution. However, rather than focusing on the theoretical underpinnings of each of these fields, the following chapter will outline how qualitative and quantitative data collection and analysis methods intersected to form the basis of the study.
CHAPTER III: Methodology & Findings

This study is a qualitative exploration of the ways in which pediatric health professionals come to knowledge and decisions about the HPV vaccine. This study was developed in conversation and collaboration with practicing and academic pediatricians, academic advisors, and two distinct peer review groups. *Pediatric Health Professionals and HPV Vaccines* received Institutional Review Board Approval from the Boston University School of Medicine. It has also been subject to weekly peer review sessions to review and discuss the methodological design, research challenges and choices, and the data analysis and writing processes as related to the project.

*Study Development: Literature Review & Initial Study Design*

The study began with an intensive literature review in early 2010 to identify current research findings and methodologies related to HPV vaccines and the role of pediatric physicians in their administration. The initial literature review found a large amount of clinical research regarding the presence of HPV in various patient populations and the role of the HPV vaccines on an international scale. There was also a wealth of research regarding familial decision-making and vaccine awareness in reference to the HPV vaccines for girls (e.g. Cates 2010; Gamble 2010). There was also emerging research on how boys and their physicians view the vaccines (Weiss 2010; Liddon et al. 2010). Given the recent timeframe in which these vaccines were approved, most of the initial literature data was survey based and quantitative in format; there were few published studies that questioned the decisions and role of the physician as an arbiter in the use of HPV vaccines specifically.
The literature review also revealed that there was little qualitative research concerning HPV and patient populations, and even less qualitative research that explores the role of the physician or their relationship to the HPV vaccines. An exploratory conversation with a practicing pediatrician in the Boston area revealed that while certain practices, clinics, or professional associations may have an accepted vaccination schedule, there are conscious and unconscious influences upon a physician’s presentation of vaccine to patients and their prescribing habits. These influences and habits may not be obvious to the physician in their day-to-day practice, but could reveal themselves in qualitative interviews or observations and through a quantitative review of prescribing patterns (Hunt 2010; Hersh et al 2009; Tanabe 2011).

I also followed popular news outlets for stories related to physician decision-making and to the HPV vaccines. To get a sense of the media arc related to the development, approval, and eventual use of the HPV vaccines, background news articles were collected from the archives of the New York Times website beginning in spring of 2006 and extending through December 2011. This review also helped to inform the research question by placing it in a popular news context, in addition to medical and academic contexts.

Study Design

The study was initially designed as a four-pronged exploration of the ways in which providers gather knowledge and come to decisions through the lens of the Human Papillomavirus (HPV) vaccine. Each section of the study was optional, and participation in any one portion did not necessitate participation in any other. I designed the study to
include medical practitioners who identified their practice or focus of research interest as a pediatric or adolescent population, but did not make any restrictions based on age, ethnicity or other demographic considerations about the participants.

Due to institutional challenges and the time constraints on the data collection period, several revisions were made to the study design through elimination of some of the proposed data collection methods. I will first outline the initial study design and, in a later section, discuss the ways in which this design was revised during the study period. Because there are multiple sources of information that both inform decisions and later measure these same decisions, this study was initially designed to gather data from several of these sources in order to triangulate the collected data and increase the reliability of the findings. In anthropology, data triangulation involves using several different types of data or sources of information in order to increase the validity of the original data set and the final analysis.

The first section of the study proposed to engage in participant observation in two to three pediatric practices in the Boston area. In general, participant observation involves extended periods of “hanging out” in a fieldwork location to gain a deep understanding of the environment, its participants, and to develop a context within which the other data is understood. I planned to spend several hours each week observing how each pediatric office functioned from administrative, patient, and practitioner points of view. This would have involved spending time in patient waiting areas, in practitioner common spaces such as lunch rooms or front desks, attending practice meetings, get-togethers or learning seminars, and shadowing practitioners during their daily appointments all to gain
a deep knowledge of the environment in which practitioners operate and make their
decisions regarding their own values as medical practitioners and patient care.

The second and primary data collection method for this study, which is reflective
of anthropological studies as a whole, was qualitative interviews. I designed the interview
as semi-structured and the questions as open-ended in nature, which gave participants the
opportunity to narrate their answers in a more reflective manner. Open-ended questions
are designed to foster a dialogue between the investigator and the research participant
(Schensul et al. 1999), which often leads to a more comfortable interview setting. The
purpose of the interview was to elicit specific themes and stories related to the
participants’ professional and personal decision-making habits with a specific emphasis
on decision-making surrounding the HPV vaccines. As each participant has an
independent set of experiences and views, I planned to incorporate any interesting or
salient questions that had developed from previous interviews into future discussions or
interviews with providers as a method of member-checking the data.

The survey was the third portion of the study and was developed in response to
some concerns from potential participants and advisors that physicians are often unable to
substantively contribute to qualitative research projects due to the time commitment
involved. The survey was used to provide physicians who were unable to devote more
than a few minutes to the study to contribute their views on broad topics related to the
research question. It was meant to take about 10-15 minutes to complete, was completely
anonymous and was published through an online survey program. It included questions
about that practitioners’ academic and professional background, practice environments,
sources of knowledge or continuing education, and familiarity with HPV vaccines. The survey was designed to produce quantitative data in dialogue with the qualitative data produced from the semi-structured interviews. The survey was to be distributed to individual practitioners via an email link, though there was no way for the investigator to know whether or not a participant had completed the survey.

The final component to the initial study design was a vaccine ordering data review for each participant. This would include a review of ordering data related to the HPV vaccines and was to be identified by practitioner name but not be connected to any patient data. This review was meant to compare the quantitative data of individual vaccine ordering to the qualitative data gathered during interviews and participant observations. During the initial research to develop this study, it was apparent that while the majority of practitioners were in favor of the HPV vaccines, few were vaccinating their patient populations at a rate comparable to that of other vaccines. There are several factors that contribute to this which will be discussed at length, but for the purposes of my study, it was important to develop a second quantitative analytic tool to examine how practitioners’ personal and professional decisions affect their ordering behaviors.

**Recruitment Techniques & Participants**

The study was designed to include approximately 75 participants at about 5 different pediatric practices in the Boston area. This number was chosen based on initial conversations regarding practice interest in the project, the number of participants needed for a valid sample across each portion of the initial study design, as well as advice from academic advisors and the Boston University IRB.
Participants were recruited using both convenience and snowball sampling methods. Convenience sampling is a method of sampling that relies on the easy accessibility of participants, particularly identified as those that readily volunteer to participate upon hearing of the study. For this particular study, snowball sampling was more useful given that it relies on interpersonal relationships as a way of recruiting individuals already connected to the participant sample.

Pediatric practices and individual practitioners in the Boston area were contacted through personal and academic references and these conversations occurred over the phone and through e-mail communications. These conversations were exploratory and gauged the potential participant’s interest in learning more details. Potential participants, individual physicians and practice representatives or managers, were contacted through an email invitation to formally participate in the study. This invitation included a description of the study as well as a request for any questions regarding requirements for participation. A follow-up email was sent one to two weeks later, with a final contact attempt occurring no more than two months after the initial contact.

Several practices initially expressed interest in participating in each portion of the project. However, several of these practices were unable to participate due to institutional challenges, such as additional independent IRB reviews of the study, a queue of other researchers already working in their locations, no one available on site to serve as a primary contact person or coordinator, and the lack of a “seasoned” investigator acting as principal investigator for the study.
Of approximately fifteen practices contacted, two agreed to participate in each section of the initial study design, and additional individual participants not associated with a specific field site were recruited through either snowball or convenience sampling. A total of 14 providers agreed to participate in various capacities. Of those 14 participants: one was unable to participate in any portion of the project due to schedule constraints, two completed an interview and allowed me to shadow their daily movements, two allowed me to shadow their daily movements but were unable to schedule time for an interview, and nine participants completed an interview only. Because one of the participants was unable to contribute to the study’s data collection process, I used the 13 participants as my sample. The small sample is a reflection of the limited time span allotted for data collection and the multitude of time constraints on pediatric providers’ schedules, which will be discussed in a later chapter.

Some of the 13 participants were located in the private practices, but many were from various departments within teaching hospitals in the Boston area. Three participants, two physicians and one nurse practitioner, were from a private pediatric practice in the immediate Boston area. Two other participants, both physicians, were located at a private practice in Boston’s metro west area. The eight additional practitioners participated in the study independently of their practice locations’ participation. Five of these practitioners are affiliated with a large Boston teaching hospital: two as practicing pediatricians, one as a pediatric researcher, one as a family medicine provider in a community health clinic, and one as an obstetrician at a

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7 All individual or practice names referenced in this study are pseudonyms.
community health clinic. Of the remaining three participants, one is a nurse practitioner working with a mostly pediatric population at a private community health center, one is a pediatric physician working in a children’s hospital in the Boston area, and another is a pediatric physician working at a community health center affiliated with a large Boston teaching hospital.

*Study Design Revisions & Data Collection*

Data were collected from June through October of 2011 through interviews and participant observation at participating practice locations as well as from publicly accessible meetings, presentations, and online sources relevant to the research questions. Due to the time constraints around the study’s data collection period and the time constraints on pediatric providers during their patients’ summer vacation period (June – August), several sections of this study had to be discarded or revised. The study revisions occurred during the data collection period and were completed in consultation with academic advisors. No changes to the IRB approved structure of the project were implemented.

The physician ordering review was the first section of the study to be discarded after it became apparent that many participants, especially those in private practice, were unable to generate reports specific to the HPV vaccine that did not include patient data or other irrelevant information. The survey was also discarded after several practices and individual participants noted reluctance to share e-mail addresses for anything other than basic study-related correspondence. Some practitioners stated that they were not sharing their e-mail addresses because they already received so many requests for completing an
online survey, and were trying to reduce the amount of e-mail they receive as a time-saving mechanism.

A few providers expressed discomfort with the participant observation portion of the study, primarily rooted in their unfamiliarity with traditional anthropological fieldwork and data collection methods. Participant observation thus became a secondary method of data collection and occurred mostly through passive observations in waiting rooms, with occasional “shadowing” of provider visits. Secondary forms of data collection included media analysis of practice websites, videos of HPV commercials, and an archival review of HPV vaccine coverage in the New York Times over the last six years. Participating practices’ websites, where they post information about their vaccine policies, adolescent health disclosure guidelines, and other pertinent information for parents or patients, are an important source of data regarding the theory of how a practice operates in comparison to the “on the ground” realities of pediatric practice. I will discuss the roles of media and the relationship between pediatric theories and practice at length in later chapters.

The primary method of data collection was qualitative, open-ended interviews with healthcare providers who specialize in pediatrics or have a stated interest in issues that affect pediatric or adolescent populations. The interviews generally lasted between thirty and fifty minutes, and each began with a review of study’s informed consent form. Written consent forms were reviewed and completed for each participant, and the participant was encouraged to maintain a copy for their records. Prior to beginning each interview, I asked each provider if recording the interview would be acceptable and also
asked their permission to take notes during our conversations. Interview participants were sent a brief note of thanks along with a small gift valued at $5 for their time and contributions to the research project immediately following each interview. Each participant was also mailed a copy of their interview transcript(s) as an additional consideration for their participation in the project. Participants were encouraged to clarify or expand any statements from their transcript they felt did not elucidate their understandings, though none of the participants made changes or additions to their transcript, and there were no requests to exclude any portion of any transcript.

Data Analysis

During the course of collecting interview data, I used theoretical sampling as a tool to further explore themes or topics that came up already collected data to direct the next components of data collection (Coyne 1997: 625). I primarily used theoretical sampling to refine my interview questions and direct the development of new questions as I learned what was important about this topic for pediatric providers. This form of ongoing analysis allowed for the refinement and comparison of codes and thematic elements as more data became available. This sampling method also allowed for relationships in the data to emerge and to more precisely orient the eventual theoretical analysis.

As a confidentiality measure, all audio files and any accompanying field notes were de-identified and assigned an identification code assigned to each participant. All interview recordings were transcribed verbatim using ExpressScribe transcription software, which is widely available at no cost and has a simple user interface, or were
transcribed by a professional transcriptionist and spot-checked for accuracy. The transcription layout was maintained across all files to facilitate the analysis process. The transcripts were printed for coding purposes, and an accompanying digital codebook was developed to track and revise codes as necessary. The transcripts were coded for thematic content using several coding methods; each method was explicitly chosen to elucidate a particular type of knowledge that may or may not be present in each data set, and each is intimately related to the phenomena identified in the study’s original research questions.

I first reviewed each transcript and highlighted interesting quotations or recurrent phraseology across the different participants’ interviews. This allowed me to form initial impressions about what practitioners saw as important in their practices and how they interpreted the purposes of my project. This falls under the rubric of “initial” coding (Saldana 2009), in which the researcher begins the coding process by reflecting on the contents of the data and beginning to develop analytic approaches or directions. I next employed In Vivo coding to highlight the participant’s own voices as the coding mechanism. This allowed me to focus in on what the participants were highlighting as the important components of my research question, or even components of the topic that I had not previously explored or even considered.

The next coding method involved combing through the transcripts to apply descriptive, or “topic,” codes to my data. This style of coding summarizes the most basic topics in the data, which served to outline the main nouns that participants used to describe the content of their day-to-day experiences as a health provider. This level of coding was also important because it enabled me to separate the specific goals of my
study from what my participants were highlighting as important topics. As codes were identified, they were transferred to two locations: first, the code word (or words) and their limiting definitions were added to an Excel spreadsheet for efficient tracking and future use, and second, the codes and their accompanying definitions were transcribed onto index cards for later grouping during the theme development process.

I next revisited my transcripts for another coding application known as process coding in which gerunds, or “-ing” words, are used to describe the actions that are occurring within the data (Saldana 2009, 77; citing Charmaz 2002). Because the broad focus of this study is decision-making, which is a type of deductive process, process coding is a vital component to understanding how the constantly shifting world of pediatric practitioners operates. The last method of first cycle coding was meant to elucidate provider feelings or experiences about the topic under discussion, which is known as emotion coding. This type of coding is particularly salient for studies that “explore intrapersonal and interpersonal participant experiences and actions” (Saldana 2009, 86), and is thus more than appropriate for this study. The same code tracking methods were also used for these strategies.

Theoretical coding is generally used in a grounded theory based study as a method for collapsing initial codes or themes under umbrella topics during the study’s data collection process; however, I employed the theoretical coding method as a final step meant to elucidate themes from the results of the first cycle methods. From the Excel spreadsheet and the index cards that contained my individual codes and their definitions,
I developed some initial themes through a bucketing exercise in which I grouped codes together that, at first impression, seemed to have similar origins or processes.

I identified four major themes from this exercise, all of which were process oriented. I then created a second Excel spreadsheet with these themes as major headings, and re-grouped the individual codes under these headings. Codes were assigned to at least one, and at most two, of the headings as a method of acknowledging the high level of crossover occurring within my data. Within the four major processes that grew out of my coding data, I developed sub-themes by collapsing codes together that were similar in nature, definition or process. For each of the four themes, at least two and at most three sub-themes were identified, and these themes and sub-themes form an outline of the narrative structure through which my study’s findings are addressed.

The next two chapters focus on the stories and processes that the participants shared with me over the course of this study. It will delve into how the previously discussed data collection processes, interview themes and participant stories work together to form a picture of pediatric practice that is both complete and incomplete.
CHAPTER IV: Learning to Know

Becoming a biomedical practitioner in the United States requires a certain amount of chutzpah. Not only has the practice of medicine become a political tool, but the business of medicine has also overtaken the individual provider’s ability to practice their craft unencumbered. Working within the current climate of primary pediatric care tests providers emotionally, intellectually and professionally and providers seem to be constantly, and collectively, fighting to maintain their grip on the profession of medicine.

In speaking with and observing the participants of this study, becoming a doctor or nurse of any specialty requires an unending interest in acquiring, processing, and regurgitating multitudes of relevant and insignificant information to audiences as diverse as the information itself, along with that healthy dose of chutzpah. This chapter explores how medical knowledge is acquired, maintained, and used as a tool to establish interpersonal relationships, professional identities, and decision-making authority within the practice of pediatrics. Broadly, I argue that the ability of providers to “know,” or navigate, these relationships and identities is critical to contextual medical and narrative decision-making.

The first section of this chapter will discuss the processes used by physicians to describe how they come to learn to narrate clinical knowledge and experiences. Later sections will discuss the processes by which nurse practitioners navigate “knowing” their role as one distinct from physicians, as well as the continuing medical education process through which medical experts maintain their knowledge base.
Creating the Expert: Physician Knowledge

Crafting a narrative around a clinical situation requires both medical knowledge and knowledge of one’s individual and collective patients. But how do physicians come to “know” their patients? How do they come to understand what components of social experience and health care are important to their patients, while also attending to their own goals or benchmarks for the visit? While these questions were not a direct focus of this project, they came to form the primary frame through which providers discussed their experiences with decision making and medical products such as vaccines. Physician participants in this study used several strategies for coming to “know” their patients, and also used somewhat similar strategies for how they come to acquire new or revised medical knowledge.

One could argue that the acquisition of medical knowledge begins well before a future doctor applies and is accepted to medical school. Of those doctors that participated in this study, most indicated that they had taken preparatory classes in the “hard” sciences such as biology and chemistry as a method of acquiring the required knowledge for entrance to medical school. Many also pursued activities meant to bolster their credentials as aspiring physicians, such as hospital or clinic volunteer work, in which they began to directly interact with patients. Entering medical school is both the culmination and beginning of efforts to understand what it means to be a professional physician; ultimately, medical school curricula aspire to create a common set of knowledge and experiences on which physicians can draw in their day-to-day performance of medical practice.
Dr. Weiss, a pediatrician who has worked at a large teaching hospital in Boston for the majority of his career, supervises and advises third-year medical students in the clinic as they begin the practice based component of their medical education, and the beginning of their professional career. As part of a seminar on “personal and professional development,” this doctor encourages a narrative based reflection process as a method of exploring the transformation of individuals into medical students and then clinicians. His explanation of this seminar is worth quoting at length here:

KET: Narrative reflective process – would you describe that a little?

Weiss: Sure. Students are asked by me to think about sort of the question you asked not why did you become a doctor, but what’s happening to you in the process of your education? It’s a critical year that we’re doing it because it’s a transition between basic sciences and classroom to all of a sudden taking on the mantle and the role of a clinician, except they’re totally unprepared to do it, and yet they’re thrown in.

That process of throwing them in, which is an important process, has dangers and risks and opportunities and wonderful things and difficult things or challenging things. It’s important for the students to have an opportunity to explore with other students, in my view, what is happening to them as they become doctors.

They are particularly involved with the human condition and how the system works and how professionals in the hospital are professional or nonprofessional, who their role models are, what they like or dislike about practice and how they are addressing their feelings based on their experiences, some of which can be quite challenging, like the death of a patient.

The process of shifting one’s identity from that of medical student to that of physician, the “throwing them in,” is a significant moment in the creation of the physician expert. It

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8 In fact, while the fieldwork and data analysis portions of this study were in progress, The Johns Hopkins University Press introduced a new quarterly journal, *Narrative Inquiry in Bioethics*, dedicated to the use of narrative and qualitative research in understanding clinical issues and bioethics.
signals a shift toward knowing how to perform one’s status as a clinical professional, including testing of the parameters around the ability to understand and explain the events in their practice.

While this study does not focus on the experience of medical school in examining physician decision-making, it is interested in how physicians come to understand their profession and the role of expert knowledge in medical decision making. Mary Jo- DelVecchio Good’s study of medical students’ narrative strategies (1995) provides a useful framework for beginning to understand the particular strategies used by physician participants to discuss their practice. In a study of Harvard Medical School’s implementation of the “New Pathway” curriculum in the late 1980s, which began to shift medical schools’ learning focus from lecture based to case and problem based learning, DelVecchio Good argues that learning how to craft a patient or case based narrative is one of the key components of medical school education. There are several types of narratives employed in clinical training and practice, including the presentation of a patient’s case to other students and physicians, and the writing of a medical note reflecting the possibilities for potential diagnoses or care decisions.

Of each narrative type learned in medical school, the case presentation was the most represented in both fieldwork observations and qualitative interviews with pediatric physicians and nurse practitioners, primarily because it lives in the domain of conversation, rather than a written note, format. One pediatrician in a practice located within a hospital setting communicated that on a weekly basis, a resident “presents an interesting case from some area, usually the emergency room or the in-patient service…”
and they talk through the case with all the different faculty there.” When participants brought up these case examples, they were often used to illustrate a particular thought or opinion about patient specific issues and practice or professional level policy, and were often preceded by some introductory remark such as “let me tell you about this” or “I know that some providers, for instance, do [x].”

It is this second introductory statement that helps flesh out how providers not only learn to become experts in presenting medical decisions or care situations, but also how to become experts in framing their practice in terms of the profession and, more specifically, “other” doctors. Rarely during an interview or even in casual discussions did pediatricians use the word “I” when describing their practice, whether they were discussing their own views or their specific practice’s policies. More often, providers used the collective “we” to describe themselves in conjunction with their practice colleagues, or used it to describe the approach of pediatricians as a whole. This theme of removing the individual from stories, and drawing on the collective profession for credibility permeates several of the example stories used throughout this study.

Another type of narrative identified during fieldwork was the narrative of patient and physician based statistics, or “number narratives.” Physicians used population level statistics as one of the strategies to identify and begin to understand their patient populations, and the health risks associated with those populations. In each of the practices where I completed fieldwork, there was also a lot of discussion regarding “benchmarking,” or the creation of practice standards of care in order to measure individual and practice performance, in conjunction with meeting quotas such as number
of flu vaccines administered or number of patients seen for an annual “well” visit, or physical. Some providers credited the focus on evidence-based medicine with using the actions and functions of primary care to inform the creation of the statistics used to measure those functions in terms of “quality” medical care. Practicing in a “busy, urban, academic medical center,” Dr. Hennessey described some ongoing quality improvement projects as “driven by a desire to make clinical practice a good as it can be and as evidenced based generally as it can be… we would choose a measure that we would think would indicate we were giving quality care and then try to maximize that measure.” Providers referenced benchmarks for specific care interventions, such as administering the flu vaccine, and reducing childhood obesity rates, when reflecting on how they evaluate the effectiveness of their practice.

These “standards of care” are also reflective of how physicians construct and justify their profession as both necessary and effective. A not insignificant component of the discussion of physician learning and knowledge is how medical providers hone their professional knowledge in the context of the clinic setting, be it a private practice, a community health center, or a practice within a teaching hospital. A later section will discuss the specific tools that providers use to maintain their clinical knowledge, but it makes sense here to focus on the how of how providers learn to maintain this knowledge, and reflect on that knowledge, particularly as it relates to the narrative forms used in practice and in discussions with other professionals and researchers.
Creating the “Other” Expert: Nurse Practitioner Ways of Knowing

Though individuals are trained to be physicians through a very particular education system, which builds on both scientific knowledge and clinical experiences, there is a growing shortage of primary care doctors in the United States as more students choose very specific medical specialties over general practice or primary care. While pediatrics is itself a specialty, it is a general practice specialty governed by a fairly standard scope of professional practice outlined by national professional societies and individual practice policies. While doctors are licensed at the state level, their scope of practice is very similar around the country and the profession is thus subject to the same shortage of primary care providers as other general primary care practices.

NPs are advanced practice nurses that, while independently licensed healthcare providers, are commonly referred to as “midlevel” providers, indicating a power structure with doctors in the lead and Registered Nurses (RNs) occupying a level of practice below NPs. The American Academy of Nurse Practitioners (AANP) states that “the term ‘midlevel provider’ implies that the care rendered by NPs is ‘less than’ some other (unstated) higher standard. In fact, the standard of care for patients treated by an NP is the same as that provided by a physician or other healthcare provider, in the same type of setting” (AANP 2009). As the AANP indicates here, the profession of Nurse Practitioner seems in direct competition with that of physicians. This tension had become more pronounced as NPs begin to practice to meet the growing need for primary care providers in the United States, and as they gain greater autonomy in clinical decision-making (Traynor et al. 2010).
In addition to the professional competition created by the interaction of NPs with MDs, the relationship between the two approaches to medicine will become more complicated as nurse practitioners take on more responsibilities within primary care practices as more individuals seek primary care services covered under new insurance options created through the Patient Protection and Affordable Care Act of 2010. However, the scope of NP practice varies significantly from state to state, with only a handful of states empowering NPs with significant scopes of practice similar to physicians in terms of insurance payments and care delivery. According to a recent policy brief from the National Institute for Health Care Reform, NPs in Massachusetts “are required to have a supervising physician who develops practice and prescribing guidelines that describe the methods NPs should follow in managing care and instances when physician referral/consultation is required” (Yee et al. 2013, Table 1).

Two of my participants were credentialed as NPs. Each works in a distinct practice environment, one in a community health center and the other in a private suburban practice, but both expressed feeling supported as independent practitioners while understanding the limitations of their practice. One of these NPs, Kelly, was a new hire for Sunshine Pediatrics at the time of our initial meeting. Just a few months prior, Kelly graduated from a Master of Science and Nurse Practitioner dual degree graduate program and had recently joined Sunshine Pediatrics. She ushered me into her exam room office with a welcoming but hesitant smile. Her short tenure at the practice meant that her patient panel was not yet full, and she was given extra time in her schedule to accommodate any visits or documentation that might take her longer to complete than the
more experienced providers. These gaps in her schedule gave Kelly the opportunity to reflect on her transition from an academic approach to medicine to a professional one, and she was especially interested in discussing nurse practitioners’ theoretical and applied approaches to primary care. As the youngest member of the practice’s doctor and nurse practitioner team, Kelly described her current role as a combination of continuing her medical education and learning to be a primary care provider.

During interviews with NPs, and with informal discussions with nurse practitioners in the participating practices, it seems that the choice to become an NP, rather than an MD or DO, is not reflective of one’s ability to gain entry to medical school or competence as a care provider. Rather, it is a conscious effort to simultaneously subvert and supplement the medical model of patient care based on increased need for primary care providers. Kelly gives some insight into this effort in saying that she “felt that I could still do what I wanted to do in the medical field by being a nurse practitioner… there’s a different sense of what a nurse practitioner does, I think sometimes, than a doctor. We follow two different models. I’m a nurse. I follow the nursing model and not the medical model.” Kelly described the nursing model as “caring” and “holistic,” and that it meant “looking at the patient, not just the medical problem.” While she was clear that her decisions were based on other factors besides the “medical problem,” Kelly indicated that she based most decisions on the standard of medical care within the practice, many of which were pre-determined depending on the patient’s history and current condition.
Another NP, Tabatha, indicated that NPs fill a need for primary care providers, and also described the NP “philosophy” as “a little different than physicians’… the idea is that we look at the patient in a holistic manner, to try to both diagnose and help them with an acute problem in the setting of their entire life, but then to go further and look at the entire life, and try to figure out ways to prevent adverse health outcomes.” Tabatha, unlike Kelly, did not want anything to do with medicine as she grew up and started her undergraduate studies. Both of her parents worked in the medical field and she had little interest in following their paths until interacting with a nurse practitioner during an internship. She describes the NP model of education as “relatively short and relatively focused so that you [new NPs] can get out a little faster and start practicing.”

The NP “philosophy” is clearly differentiated from, but related to, the processes that that inform medical decision-making by physicians. Not only do both Kelly and Tabatha indicate that nurse practitioners are more holistic in their approach, but they also indicate that the role fills a growing need within the medical field. While they say that the nursing and physician approaches to medicine are theoretically distinct, they also indicated that in terms of “practice,” doctors and nurse practitioners collaborated to determine how their clinic or health center would approach medical guidelines or policy setting for their respective practices. According to Kelly, these collaborations at Sunshine Pediatrics often occurred during a practice meeting, and included a review of the appropriate studies in conjunction with a review of their current practice and the suggestions of national pediatric organizations. Both NPs and physicians would discuss the implications and agree on a standard approach to be used for the entire practice. In the
face of fairly distinct philosophies of medical care, it is this collaboration that highlights the practical professional parallels between physicians and nurse practitioners.

Within the two pediatric practices at which I completed fieldwork, Sunshine Pediatrics had a formal training program and a specific role for nurse practitioners like Kelly. The other practice, Pediatricians of Boston, however, purposely did not employ Nurse Practitioners. In fact, one of the Registered Nurses (RN) at this second practice was near completion of a NP training program and, at the time of this study, was in the process of finding a job at a different practice in order to make use of her expanded skill set. In a passing but telling remark, one practice leader here mentioned that while they were sorry to see this nurse go, there was no role for her within their practice’s doctor-nurse focused model of medical care. This practice’s approach to care, however, seemed to incorporate many of the characteristics valued by NPs, such as a focus on the patient rather than the medical problem, and an understanding of each patient’s life situation as a driving factor in their health care.

There are several interesting themes that emerge from Kelly and Tabatha’s experiences and Pediatricians of Boston’s conscious decision not to utilize NPs. The first is quantity of care. While the need for primary care is expanding around the country, each pediatric office is a self-contained system that may or may not require the support of NPs for delivery of primary care. Practices, particularly private practices such as Sunshine Pediatrics and Pediatricians of Boston, are able to decide their ideal volume of patients in order to sustain their preferred model of care delivery, though the inclusion or exclusion of NPs may be a result of this decision or a driving factor in determining that volume.
The second thread here is quality of care as related to professional identity. In implementing a training program and providing ongoing clinical and professional support, Sunshine Pediatrics sees a clear role for Nurse Practitioners in supporting the practice’s primary care delivery. On the other hand, the exclusion of Nurse Practitioners from a particular practice could point to a devaluation of the nursing approach in favor of the medical model, or an incorporation of the nursing model into the physicians’ practice.

In incorporating some tenets of the NP model into their practice, it seems that the physicians at Pediatricians of Boston were simultaneously circumventing the need for primary care support while addressing the subliminal concern of professional encroachment on the medical profession by nurse practitioners. While medical school training teaches doctors how to “know” medicine and what it means to be a practicing physician, the education of nurse practitioners seems focused more on the day-to-day delivery of primary care. The exclusion of NPs from some practices is thus not only indicative of the limits to where NPs can practice, but is also telling of medical doctors’ desire to maintain their professional jurisdiction as the expert.

“If you're going to be a bear, be a grizzly”

Maintaining this jurisdiction in the face of physician resource constraints is a challenge for pediatric providers. But this is not just a matter of excluding non-MD or DO providers from practicing primary care; it is also in the best interest of doctors to maintain their knowledge base as a method of maintaining their clinical expertise, and, in turn, their professional jurisdiction. In an attempt to get at the process by which pediatric providers maintain their knowledge, I asked many of my participants a broad based
question about how they researched clinical questions, or how they kept up to date on the
information relevant for their field. This chapter will review several of these methods
within the context of pediatric practice and decision-making, but will only tangentially
discuss how providers use news media as a source of information. I will discuss this at
the end of Chapter V in the context of how providers use media representations of their
field to negotiate and navigate how they share information with patients and families.

During a discussion of the day-to-day ramifications of some state based proposals
to mandate the HPV vaccines for girls of a certain age, one participant tied in the
importance of maintaining one’s professional knowledge in order to convey information
effectively, suggesting that there was some discrepancy between what was communicated
to doctors through research versus what was communicated to patients in the clinic. As
she discussed this issue, she thought back to a doctor from residency and related that “Dr.
Smith had a saying which was ‘If you’re gonna be a bear, be a grizzly.’ Like be
consistent. If you think something is important, do it. Don’t, just because it’s gonna be
hard to do, wimp out.” I find this particular statement to be telling of a number of trends
related to professionalism and decision-making highlighted by the physician and nurse
practitioner participants in this study.

The first is that of ensuring one’s status as a professional through “consistent”
actions, or, as the case may be, decisions. But making consistent decisions is predicated
on the maintenance of one’s clinical expertise and knowledge of current “practice.” In
this instance, I refer to practice as both the individual provider’s practice within their
panel of patients and practice environment, as well as current “best” practices
recommended by professional governing bodies such as the American Medical Association (AMA) or the American Academy of Pediatrics (AAP).

Both physicians and nurse practitioners (collectively, clinicians) are mandated and encouraged to continue learning and update their practice according to the latest available guidelines and study findings. The mandated component of ongoing clinician learning takes place in courses that qualify as “continuing medical education” (CME), for which providers earn credits and must submit documentation as completed to their licensing body. CME, however, does not necessarily get at the voluntary and real time, situational learning that my participants indicated was a valuable and necessary part of their practice.

While discussing the “art,” or ambiguity of medicine and decision-making versus the science of clinical knowledge in a group practice setting, one physician participant highlighted the value of conferring with practice peers:

One of the nice things, I think, about working in a group practice like this is the chance to really stand in the back between patients and say, ‘hey, I have this kid with x, what do you think?’ or ‘what would you do?’ I think there’s a huge amount of value to that because there’s often not a consensus as to what you should do [for a patient]. So running ideas off of each other really makes it a lot easier to do.

Conferring within one’s practice seems to be the preferred method of real-time problem solving or diagnosis identification (in order to facilitate clinical decision making) among this study population.

Outside of this process, much of the non-CME learning discussed by my participants revolved around using practice based resources to understand a particular situation; a patient may present with an odd symptom or a set of complications and need an immediate answer to the clinical question at hand, driving the clinician to seek
immediate information or knowledge. One method of doing this is through practice discussion, but another is the use of real time learning through the practice’s electronic medical record (EMR) or access to a tool called “Up To Date”^9. Up To Date is an internet based tool set up like a medical search engine: members can either manually search for a topic or input a clinical question or area and the program will provide a synthesized, evidence based summary of the search along with decision or care recommendations for the clinician. Most of the clinicians in this study referred to “up to date” as their preferred tool for brief clinical guidance on an immediate issue.

While the practice of pediatrics is practically carried out an individual level, there is also the expectation that providers manage their time effectively such that they are able to know both patient information and clinical knowledge. This “just do it” mentality leads to clinicians understanding that their knowledge maintenance is an individual responsibility. However, the tools that clinicians use to manage their learning time, given constant resource constraints and clinical responsibilities, is an interesting mini-study in the not insignificant distinctions between practicing pediatrics in hospitals, community health centers, and private practice.

Journal reading is hit or miss in this particular sample of participants. Of those providers that regularly read journal articles, they had a particular journal to which they subscribed, or kept up with articles specific to an area of interest such as childhood diabetes or asthma. One nurse practitioner finds that while journal reading is clinically interesting, it is not practically useful in terms of “the patient in front of you,” and she

^9 Basic access to UpToDate available here: [http://www.uptodate.com/home](http://www.uptodate.com/home)
preferred daily digest e-mails that summarized the most recent study findings or recommendations. A family medicine physician a few years into semi-retirement gestured to a three foot stack of unread journals sitting just to the right of his desk, and said he “was a little behind.” A couple of the younger participants in this project indicated that they were not as involved with reading journal articles as they were with producing journal articles.

But for learning that alters the practice of pediatrics, or for new data that may affect one’s sub-specialty within the field, a focus on published results is less about individual feelings on an article than it is about the “buzz [around that article or finding]” as one participant put it. She went on to describe how people are talking about them [articles] in the office. We might do a Journal Club on them. You start to hear about them wherever you go. So then you might go and dig out the paper. But generally, in a community of academics, there becomes consensus on it [an article’s findings or recommendation]. I feel like it was a lot about the osmosis when it really comes down to things that change practice.

This statement about “osmosis” of new study findings that may affect clinical practice has been explored previously (Gabbay and le May 2004), but is an interesting shift in my participants’ collective narratives about how they handle the volume of new and updated information that permeates their practices.

To deal further with the deluge of clinical information that makes its way into clinicians’ e-mail inboxes and home and practice mailboxes, some of my participants relied on meta-analysis type studies or on guidance from professional organizations. Here is where the distinction between private practice and community or hospital based practices differ. Each of the private practice clinicians I spoke with gave the distinct
impression that, while they had hospital learning resources (such as grand rounds) at their disposal, they were more inclined to review the recommendations of a professional organization and discuss internally how to implement any changes or updates to their practice. Within the sample of hospital or community health center clinicians, it seemed that there was a somewhat more varied approach to acquiring and processing new or updated clinical information.

The professional distinctions between physicians and nurse practitioners are philosophically obvious, but the line of demarcation between the credentials blurs in a discussion of clinical practice and decision-making. Beyond academic training and the day-to-day acquisition of clinical knowledge, how do pediatric providers continue to learn and identify those data important enough to narrate to patients? And how does this communication process divert attention from provider knowledge or acceptance of policy to patient acceptance of a clinical therapy or product?

This chapter discussed various ways in which pediatric physicians and nurse practitioners come to be identified as distinct medical experts that are once professionally competitive but practically aligned through pediatric practice operations and continued learning processes. The next chapter will discuss how clinical knowledge is shared with patients, and how the HPV vaccine provides a useful case study for understanding how physicians use history and stories to justify their professional status and provide a basis for their limited scope of day-to-day decision making.
CHAPTER V: Knowing to Share

The previous chapter explored how information acquisition and management for both doctors and Nurse Practitioners contributes to the development of one’s professional identity. This chapter will build on that discussion to argue that this identity enables providers to share information in the form of what Cheryl Mattingly calls “narrative reasoning” (1998). While individual decisions are often pre-determined by professional or practice guidelines around “best” practice, the provider’s narrative framing of clinical practice and decisions reflects the wide range of experiences and knowledge they bring to each patient encounter.

Practicing Knowledge

For children, going to the doctor is a brief introduction to the intimidation of the Socratic Method. Providers ask a barrage of questions, probing about school, friends, emotions, injuries and what life at home is like, in an attempt to extract a comprehensive life picture from somewhat reluctant respondents. They often walk a fine line between having a discussion with the child and listening to the supplemental answers provided by any caregivers or parents that may be present, and it is this negotiation that both empowers and restricts physicians and nurse practitioners in sharing their expertise.

Part of this negotiation occurs in the theoretical space of one’s practice. I heard from a couple of providers that even if they had access to all of the most up to date information, it still might not assist in a particular situation for a particular patient. The “art” side of medicine was not a prominent theme across the sample of study participants, but the process of how clinicians share knowledge with others was a significant
component of each interview and fieldwork discussion. Those clinicians that did discuss the “art” of medicine as equal to the “science” of medicine seemed to have a clear understanding of the limitations of their medical knowledge in favor of other approaches. One family medicine practitioner stated that becoming a doctor “combined science and people parts of things with opportunities for social policy as well as healing. It’s able to integrate a variety of dimensions, including ethics, religion, spirituality, psychosocial issues, cultural issues.”

It is these other dimensions that most providers employed when reflecting on how they use their expertise to perform their practice. Much as clinicians did during their medical school training, the performance of knowledge in practice is a significant part of the day-to-day experience of being a pediatric professional, though the focus seems to shift to performing knowledge to meet standards, or to share evidence with patients in order to substantiate their decisions. The next two sections of this chapter will review two ways that clinicians “perform” evidence: one through a comparative case study of the Hepatitis B vaccine and the HPV vaccine, and one through a discussion of two types of media evidence used by clinicians to negotiate their patient interactions around the HPV vaccine.

_Narrating history: Hepatitis B and HPV_

Beyond the stories about how learning and professional interactions affect their every day practices, clinicians also shared with me stories of specific instances in which the history of their field, and the history of vaccines in particular, served as a point of entry for discussions with other providers or with patients and families. And while many
providers had stories to share regarding how they present the HPV vaccines to their patients, a few participants used the historical, medical and social connections between the HPV vaccine and the introduction of the Hepatitis B virus (hereinafter, HBV) vaccine in the 1980s as illustrative of some of the issues they encounter when presenting vaccines to patients. This “institutional” knowledge of the profession is interesting in its own right, but I find it most useful in thinking about how clinicians use that professional history to navigate discussions of their current practice.

One pediatrician first brought the HBV and HPV vaccine comparison to my attention amidst a discussion of the HPV vaccine’s introduction to the pediatric vaccination “schedule” by the Advisory Committee on Immunization Practices (ACIP), a Centers for Disease Control and Prevention (CDC) committee that makes recommendations about vaccine usage to control diseases in the United States. The pediatric vaccination schedule is just that – a listing of all of the vaccines recommended for children and the various ages at which each should be administered. She found parental resistance to the HPV vaccine “so fascinating because this was a vaccine that was being given to prevent an STD, there was a resistance to this vaccine that doesn’t really make sense… we would say to people, ‘well, we give the Hepatitis B vaccine basically for exactly the same reason, and we have been for a long time’.” Here, the comparison for this provider lies in the disease being targeted by the vaccine.

Similar to HPV, Hepatitis B is transmitted through blood and other bodily fluids, and is a significant global health risk. A 2008 study approximates that “4.5 million new HBV infections occur worldwide each year, of which a quarter progresses to liver
disease” (Zanetti et al., 2008; also see Romano et al. 2011). Approved for use by the FDA in 1981, the HBV vaccine prevents chronic Hepatitis B, which is a leading cause of both chronic liver disease and liver cancer. The HBV vaccine was originally targeted to high risk groups and was later recommended for use in infants and adolescents in the early 1990s (WHO 2009); it is currently administered to most newborns within 24 hours of birth with an ongoing series of doses throughout early childhood. It is not only framed as a disease preventing vaccine, but also as the first cancer prevention vaccine, since in preventing liver disease, the incidence of liver cancer secondary to liver disease and cirrhosis is also reduced.

There have been a number of studies completed on the relationship, both scientific and social, between the HPV and HBV vaccines, a couple of which are worth highlighting here as they are useful in understanding the academic relationship between these vaccines, if not the applied relationship used in practices to present either to patients. Heffernan and colleagues (2010) drew on the historical “lessons” from the introduction of the HBV vaccine to make very broad recommendations about global planning and delivery of the HPV vaccines, such as increasing affordability, targeted public health campaigns, and endorsements of the vaccine from governments in line with the recommendations of the WHO. In a similar study, Mark Kane (one of Heffernan’s colleagues) explored how bringing cost and delivery of the HPV vaccine more in line with the HBV vaccine would facilitate vaccine administration, and therefore disease reduction, in developing countries (2010) where untreated HPV and cervical cancer are significant public health issues (Zarchi et al. 2009).
In line with the recommendations for administration of the HBV vaccine to infants, my participants pointed out that not only is HBV “a sexually transmitted disease…we just vaccinate infants against it so no one even thinks about it [being a STD],” but that nobody refuses Hep-B vaccine; it’s a non-issue. I think HPV would be really interesting if we get to a time period where we move [administration] back to the infant age…originally, when Hep-B came out, it was given to teenagers, too. And then they moved it back to infancy.

The underlying message here is that there should be little to no resistance to the HPV vaccine since it is so similar in nature to the HBV vaccine: both are a series of shots to prevent sexually transmitted diseases that have causal links to different types of cancers.

Despite the scientific and social parallels between the HPV and HBV vaccines, some physicians did not see a clinical or explanatory value to the comparison and instead found value in identifying the purpose of vaccines as a whole category of preventive treatment. As one participant stated, “when I compare [the HPV vaccine] to other vaccines, I compare it in the sense of what do vaccines do [for patients]… if you know that there was something you could do for your child to prevent them from getting an illness, you probably would.” I also heard this refrain in comparisons to the flu vaccine; a couple of providers conveyed that they presented flu vaccines as not only effective for one child, but also effective for everyone’s child through “herd immunity” (Plans-Rubió 2012). That said, there were a number of clinicians for whom this comparison proved fruitful in narrating how previous professional experiences with vaccines inform their current presentation of new strategies to prevent or reduce disease.
According to several of my participants, the main link between the HPV vaccine and the HBV vaccine is the type of contagion to which the vaccine is targeted, as well as the method of disease transmission. However, there are few, if any, similarities in terms of the clinical administration and current social context surrounding these two vaccines. Noting some frustration with the influence of that social context on patients, one family medicine oriented pediatrician at a community health center relayed:

Hepatitis B vaccine [is] given to newborns… most Hepatitis B in this country is sexual, so why are we giving one sexually transmitted disease [vaccine] in infancy with patients not being that aware, and the other one at a pre-adolescent stage? Because it [Hepatitis B vaccine] was tested on [infants], and I think this is where I should know better from my patients. Part of why you tested it [the HPV vaccine] at that age was because you wanted to speed up the approval… to see the effect in teenagers. You’re not gonna go back and give it to babies and sit and wait 30 years to see if they have a better pap. You give it to 9, 10 and 16 year olds to see if they have less HPV. Great. Now test it in infants and see if we can take it away from the social context and just give it as a recommended vaccine.

Another shared a similar message:

[the HPV vaccine] has a social context, whereas the Hep-B vaccine started out having a social-political sort of context in additional to the medical one but now it’s given to babies… no one remembers that it was initially for the sexually transmitted disease.

The overt frustrations from my participants in terms of the HPV vaccine are obvious. But in speaking with these clinicians, it became clear that their frustration was not necessarily with their own explanations or comparisons of the HPV vaccine and what it does, but with families’ heightened (or even, hyper) social awareness of the HPV vaccine as a medical product with a perceived social agenda directed at adolescents.

This “agenda” is the most significant obstacle to clinicians’ effectiveness as healthcare professionals within this particular standard of pediatric care, and many felt
stymied by their inability to communicate their vaccine and disease prevention knowledge with their patients. But from where has this heightened patient awareness of the HPV vaccine come? And how do clinicians navigate the resources used by patients to overcome or compensate for that awareness within their clinical practice?

_Mediating with media_

Beyond comparative historical story telling to illustrate decisions and trends within medicine, pediatricians both use and contend with popular media representations and current events while explaining clinical products or health care options to patients and families. As previously discussed, my participants felt frustrated with their patients’ understandings of the HPV vaccines, particularly those that were skewed by the introduction of cultural and political overtones fostered in popular media. This section will discuss some of the obstacles to “effective” clinical communication and decision making as seen through the lens of two representations of the HPV vaccines in the media. The first, Merck’s 2006 “One Less” advertising campaign, introduced the HPV vaccine Gardasil to patients through television commercials and print media. The second is a discussion of the 2010 political landscape, in which several candidates for state or national political office folded the HPV vaccines into their political strategies.

The majority of the participants in this project had much to say about either or both of these representations and the communication compromises they made in discussing the HPV vaccine with their patients as a result of the One Less campaign and the political focus on their profession as pediatricians. In her previously discussed study of the medical school learning process, Mary-Jo Delvecchio Good states that “concepts
drawn from narrative analysis – plot, emplotment, and narrative time – illuminate how affect and desire play in clinical narratives, seducing patients and clinicians, enveloping both in a world of the medical imagination, with a many-possibility regime of truth, with fantastic but apparently purposeful technical acts” (2001: 400). While the media representations of the HPV vaccine tell their own story, the ways in which clinicians employed these representations in telling their own stories was equally compelling in terms of identifying where the tensions and truths for pediatric professionals lie.

The “One Less” campaign was mentioned by many of my participants as a logical jumping off point for beginning discussions with patients and their guardians, as they assumed many had either seen one of the commercials or heard about it from peers or friends. The commercials showed adolescent girls of various ages and ethnicities pursuing various activities individually and in groups, such as sports or music, all while saying to the viewer that she wants to be “one less” case of cervical cancer\textsuperscript{10}. The message, broadly, is that all young women are at risk for cervical cancer\textsuperscript{11}, and that one’s ability to overcome this risk lies in the preventive uptake (to use a clinical term) of Merck’s HPV vaccine, Gardasil.

In a study with a cancer advocacy group, anthropologist Samantha Gottlieb examines Gardasil, HPV, and cervical cancer through what she calls the patient-consumer-advocate nexus. The advocacy group “embraced Merck’s definition of [patient] empowerment and deliberately renounced political aims” in an effort to educate

\textsuperscript{10} While no longer available on the Merck website, the first Gardasil commercial can be seen here: http://www.youtube.com/watch?v=hJ8x3KR75fA.

\textsuperscript{11} For a discussion of the One Less campaign’s framing of cervical cancer risk, see Grantham et al. 2011.
patients about Gardasil in unofficial alignment with Merck’s “One Less” marketing strategy (2013: 332). Overall, Gottlieb argues that a patient’s individual identities as consumer and advocate are situated in the same vein as “corporately informed breast cancer advocacy.” This is interesting on a number of levels, but the obvious one is the opportunity that cervical cancer advocacy groups took in using the vaccine to “open up new ways of talking about HPV and brought their [the patient’s and group’s] experiences into public discourse” (Gottlieb 2013: 339). While the focus here is on patient communication strategies, the strategy of consumer groups using a pharmaceutical’s own strategy to discuss the HPV vaccine is consistent with some of the strategies relayed by my participants as moderately effective with their patients.

One such strategy is to take a holistic approach to the discussion, and fold the conversation about the HPV vaccine into a discussion of that patient’s other upcoming vaccines, or how they are feeling about their ability to recognize the changes occurring in their lives as they transition to early adolescence12. This sets the stage for patients to ask questions, and for clinicians to offer information about the vaccine, indicating a somewhat shared model of decision-making (Charles et al., 1999). One clinician, who did not seem to have a set approach to presenting the HPV vaccine, put it this way: “Some go for, and some say they want more studies done, and they want it done years down the road. Some are really open to it and some are not. You just kind of, as best as you can, describe what it is and what it prevents and given them the information.” What is difficult

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12 For the purposes of this discussion, the reader should be aware that all clinicians used the 11-year old or 12-year old annual “well” visit as their standard example when discussing the use of the HPV vaccines in their practice.
here is identifying who the “they” is in the presentation of the HPV vaccine. For this particular clinician, the “they” is clearly the patient’s guardian or parent, which speaks to the family-centered care approach prevalent within pediatrics (American Academy of Pediatrics Committee on Hospital Care and Institute for Patient- and Family-Centered Care 2012).

Another strategy is to directly engage the patient using the One Less campaign’s messaging. One pediatrician thought the campaign was “a really interesting one and kind of coincided with when it was approved [by the FDA] and then recommended by the AAP.” In trying to figure out how to initially present the vaccine to her patients, this same pediatrician relayed how she had to negotiate with families around the fact that I thought it was a really important vaccine, and this was why I thought it was important. I have to admit, I did reference the One Less campaign when it was really kind of actively being done as a way to try and promote what I thought was the important aspect of it, which was kind of the idea that really the only way to prevent HPV is through the vaccine, that a condom isn’t going to be sufficient for things like that.

Despite her self-consciousness in “admitting” that she used the One Less campaign in discussing the HPV vaccines with patients, this doctor was comfortable employing the messaging of HPV prevention through the HPV vaccine.

A more common strategy than either of these, however, is negotiating knowledge with patients and their families or guardians present at the visit. Of those clinicians that relayed some kind of story about they present the vaccine or an experience of a patient’s reaction to yet another “shot” being added to their visit, most engaged in some type of narrative priming during the annual physical visits directly preceding those at which the
adolescent would be eligible to receive the vaccine. At the 9 or 10 year old visit, some clinicians will bring up that this vaccine is part of the recommended vaccine schedule in the upcoming years, ask about any questions, or begin the negotiation process about when it should be administered. A pediatrician at a private group practice lays out her recommendations to, and negotiations with, patients in what she thought was a fairly straightforward way:

My feeling about anybody who either refuses the vaccine or asks to give it at a time other than what the recommended schedule is, is that I generally follow the recommendations of the ACIP and the AAP, and I’m gonna tell people that. I’ll often tell them why I think the timing is important. I’m more than willing to negotiate with people, if the goal in the end is achieved, which is to have their child vaccinated, then I will definitely work with them around the timing of it.

The assumption in this pediatrician’s statement is that all patients will accept and receive the HPV vaccines, regardless of any obstacles to that decision. Yet, another pediatrician, this one working in a community health center, outlined her perspective on her own and families’ decisions about the vaccine a bit more bluntly, and with more of a concern for the financial impact of the vaccine:

It’s really driven by who’s gonna pay for it [the HPV vaccine] and how strongly their [the patient’s/family’s] religion – how big their religious objection is to either all vaccines or just that particular vaccine because they don’t believe their children have sex.

It is this last statement, about religious- or sex-based objections, that points to the very real issues that clinicians encounter when their practice, and their patient, intersects with socio-political contexts framed by popular news media.

In several interviews with pediatricians and pediatric NPs, it became apparent that while the political landscape in the United States should be miles away from a discussion
of pediatrics, the two are more familiar than a first glance would suggest. This became especially true during the 2011 Republican Party’s primary race to identify the next candidate for the 2012 Presidential election, which was occurring during the last few months of the fieldwork and interviews related to this project.

One clinician brought a particular debate performance to my attention, in which one of the primary candidates made a connection between a child receiving the HPV vaccine, and that same child later developing “mental retardation,” which has no scientific or medical connection to HPV or vaccines. This clinician, getting a bit exasperated as she re-told this particular story, went on to say that someone had brought this up at a dinner party, to which she responded, “she [the politician] just set me back five years.” Given the lack of familiarity with the situation, I asked what she meant by that particular statement:

it feels like an uphill battle that we fight with a lot of parents about that. And when a big figure, someone who is respected, I think, and potentially looked up to by parents, says something like that… it can solidify that feeling within a parent, so that when I get them in the office, they’re done, they’ve made the decision…it really brought up the conversation again in a way that was completely unhelpful for my practice.

The real take-away from clinicians’ awareness of their professional representation in the media is that some feel they must be versed in these representations of their work and knowledge in order to adequately respond to inquiries from patients and “justify setbacks” to their effectiveness as health care professionals, such as lower rates of vaccination due to media representations of vaccines as dangerous. One participant went so far as to say that pediatricians almost have to participate in media representations of their profession in order to help counter those setbacks experienced by individual
providers based on poor representation of recommendations or therapies, such as the HPV vaccine.

One pediatrician, who self-identified as “a newspaper reader” jokingly shared that “a lot of people probably told you The New York Times is the best clinical journal. I think the smarter versions of the popular press are pretty important for that and helpful. Because if something’s really key, it’s gonna make the popular press.” At the same time, this pediatrician shared her concerns about the public referencing of vaccines for political gain, and, in turn, the co-opting of pediatrics to make distinctly non-medical arguments. Despite her identification as “such a blue state person in an academic sphere,” she felt that “it is important to push back against that kind of misinformation. I appreciate people being willing to say I know this is new, but I’m looking at the research and I really see no downsides to it and we need to push forward with this.”
CHAPTER VI: Conclusions

Overall, my argument and findings are not new, but validate existing work focused on how medical practitioners make decisions or communicate ideas through the frame of story-telling. Stories and narrative explanations are in constant flux; a provider may relay a story in an interview to make one point, but whether that story is used to make that point consistently is a different matter entirely. Understanding this area of story negotiation in the context of pediatric practice in Boston formed the basis for this study, and the pediatric health practitioners that allowed me insight into their individual and collective practices were more than forthcoming in sharing their understandings of learning, decision-making, and how medical products such as the HPV vaccine fits into their day-to-day practices.

Study Limitations

That said, there are several limitations to this study’s findings of which the reader should be aware. While these limitations do not necessarily detract from the general findings, it is important to keep in mind that there are additional unexplored factors that contribute to the processes and outcomes involved in physician decision making, and that the HPV vaccines are but one clinical product used by adolescent and pediatric health care providers as a starting point for decision based stories or discussions.

The popular perception that physicians, and pediatric practitioners in particular, are constantly pressed for time was borne out in this study’s population. Individual interviews were often cut short due to clinical responsibilities and participant observations with individual or groups of providers during their workdays were
complicated or impossible due to each participating provider’s schedule. The difficulty in accessing providers’ time speaks directly to the high value, both intrinsic and financial, placed on the “professional” physician’s time (DuBois 2011: 65).

However, in being unable to access some providers’ practice environments through participant observation fieldwork, there is a significant gap in understanding some of their approaches to medicine broadly, and the research questions in particular. This gap also sheds light on the difficulty in teasing out the conflation of pediatric patients as “patients and families.” Since pediatric clinicians walk a fine line between their patient population (children) and the guardians of that population, it was at times challenging to get a sense of the true audience envisioned by clinicians as they described their experiences.

Future Research Opportunities

Beyond the day-to-day data logistical and methodological constraints presented by this particular population, there are also some elements related to this researcher’s data analysis choices that shed light on opportunities for future study. As previously mentioned (see Chapter III: Methodology & Findings), gerund coding, or using “-ing” words to identify data themes, was used in addition to a general topic based coding approach. This provided insight into how events occur or were identified and relayed by study participants, which aligned with the research questions focused on deciding and communicating. While gerund coding and the resulting data analysis were the most appropriate based on the research questions and initial fieldwork impressions, focusing on processes in the data may have inadvertently excluded other important themes within
the available data set. This is an obvious opportunity for future work, and is a direct result of the types of choices made in the data analysis phase of qualitative research.

A second, and likely more significant, opportunity related to gerund coding, is the use of action as the primary source of data analysis. In particular, the shifting nature of action both limits and strengthens the analysis and arguments employed in this study. When identifying data themes or events using “-ing” words, there is an inherent focus on process and movement, regardless of that movement’s intent or directionality. Words such as “learning,” “deciding,” “explaining,” “othering” and knowing” all imply an ongoing negotiation of events or facts by the participants in order to communicate the most appropriate information within a particular context. With that in mind, I would argue that this iterative negotiation process is also an opportunity for future work.

With these opportunities for future work in mind, I appreciate that the participants found such significance in the research questions and in our conversations. Their participation and stories provide a textured insight into their individual practices, and allowed me to highlight those instances in which they do not have any latitude in terms of decision-making or the ability to offer ongoing, meaningful support to patients and families.

The day-to-day practice of pediatrics in Boston and the surrounding areas is challenging for patients and clinicians due to the medical complications that arise from the social, cultural, and economic complications that accompany life in any large city. And while medical insurance is mandated for children in the state of Massachusetts, there
is a portion of the population for whom access to pediatric medical providers is their sole avenue to access medical and social services.

During the course of this project, I heard from several participants, both NP and MD alike, working in private practice and community based health centers or teaching hospitals that their concerns for their patients’ housing situations and ability to access food (regardless of its nutritional value) was a significant obstacle to their providing good, or even adequate, health care. Their ability to point patients and families toward appropriate social resources was limited by the inability to identify causative factors in their patients’ conditions and in the limited resources to which providers had access, particularly for those in private practice. As one provider in an academic medical center relayed, he often couldn’t tell if a child’s asthma was or primary origin or the result of the child’s public housing environment, which is of notoriously low quality in terms of ventilation systems and maintenance, and he had little recourse other than to refer the case to the hospital’s medical-legal support team, whose sole function is to use legal recourse to help improve patients’ social situations (as a way of improving their health).

The ambiguity of individual patients’ life situations, and the lack of an advanced social and legal support system that can be called on by providers, work in tandem to restrict the ability of pediatricians to use their decision-making skills effectively. For one pediatrician heavily involved in public policy work, the limitations of medicine are obvious: “so much of the high risk, low income patients that we see, traditional medical care only goes so far. You have to stretch it [medicine] a bit, and so being able to think through mechanisms to change the policies that are making them sick as much as the
actual kind of prescriptions you would normally give out.” It is here where anthropologists studying the field of pediatrics may use this study’s findings to inform future work.

As the field of pediatric practice necessarily expands to include different types of primary care providers, such as nurse practitioners, and to provide health care and services to more children as they are given access to health insurance, the profession’s approach to social obstacles to health should be considered worthy of anthropologists’ attention. Since this study’s inception, more pediatric (and adult) practitioners in the Boston area have begun utilizing “connector” services that connect patients with social services via their health care system. The lens of anthropology not only attends to the day-to-day experiences of being a pediatrician, but also attends to those internal and external factors that shape the knowledge base of this population and individual providers’ interactions with their patients and their patients’ own life situations. For pediatric focused health practitioners, their scope of patient engagement may be overwhelming in volume, but is somewhat limited in terms of ability to provide comprehensive care to their most vulnerable patients.
ABBIBIOGRAPHY


13 This thesis uses the Chicago Manual of Style’s Author-Date format for all bibliographic references.


Curriculum Vitae

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Education:

**Boston University School of Medicine**, Boston, MA
May 2014 M.S. Concentration: Medical Anthropology & Cross Cultural Practice

**Colby College**, Waterville, ME
May 2009 B.A. Majors: Anthropology, Art

Experience:

**Commonwealth Care Alliance**, Boston, MA
June 2013 – Present  *Risk Adjustment Program Specialist, Medical Affairs*
June 2012 – June 2013  *Program Associate, Medical Affairs*

**Boston University School of Medicine**, Boston, MA
April 2011 – Present  *Principal Investigator, M.A. Thesis Project*: Developed and implemented an IRB approved multi-sited, qualitative research project with participants at pediatric practices in the Boston area.

**Crate & Barrel**, Chestnut Hill, MA
July 2009 – Present  *Sales Associate*: Provide customer service as part of a creative and dynamic sales team. Educate customers on current product and maintain availability knowledge.

**Colby College Department of Anthropology**, Waterville, ME
Fall 2008  *Research Assistant to Visiting Professor Brian Karl*: Researched and compiled annotated bibliographies of journal articles, books and films as part of the development of three course syllabi.

**Colby College Museum of Art**, Waterville, ME
Spring 2008  *Student Curator*: Worked as part of a curatorial team to develop a dual-sited exhibition entitled *Ink Tales*. Assembled exhibition related materials including an interactive family guide, exhibit website and object wall text.

**Intern to Museum Registrar**: Aided in the creation of new museum database and website concentrating on object data and images; completed initial copyright and artist research for 50th anniversary catalogue.