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Needling doubts: A sociological examination of parental resistance to childhood immunizations

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**NEEDLING DOUBTS:
A SOCIOLOGICAL EXAMINATION OF PARENTAL RESISTANCE TO
CHILDHOOD IMMUNIZATIONS**

BY

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DISSERTATION

**Submitted to the University of New Hampshire
in Partial Fulfillment of
the Requirements for the Degree of**

**Doctor of Philosophy
in
Sociology**

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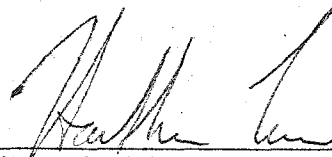
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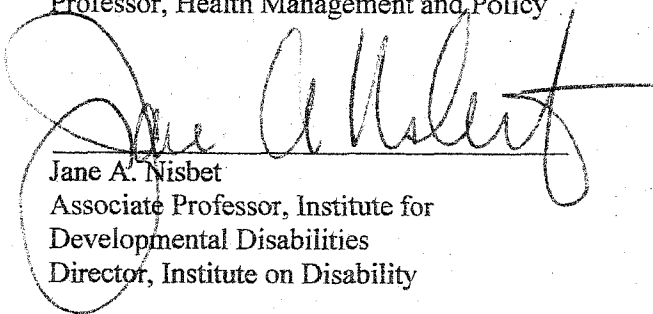
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DEDICATION

This work is dedicated to the spirits of several people to whom I owe pieces of my heart. To May and Doots, for showing me the beauty and joy in the free spirits of independent women. To Grump, for always being proud of me, no matter what, whether she approved or not. To Grandpa, for teaching me to fearlessly explore the world and never apologize for being who I am. To Kathryn Hoye Pichette, Ph.D. and Lucien O. Pichette for their passion and zeal, for each other and the world.

I draw on each of you for strength, courage, and wisdom. Thank you for contributing to who I am and shaping who I hope to become.

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ABSTRACT

NEEDLING DOUBTS:

A SOCIOLOGICAL EXAMINATION OF PARENTAL RESISTANCE TO
CHILDHOOD IMMUNIZATIONS

by

Catherine L. Moran

University of New Hampshire, December 2004

Within recent years, a group of parents who question or oppose vaccination has emerged in the United States. While recently receiving attention within medicine and public health, parental questioning of and resistance to childhood immunization is a trend that has yet to be examined within sociology. This dissertation explores the role of parental characteristics, beliefs, and attitudes on resistance to pediatric immunization.

Thirty-five in-depth interviews with parents who postponed or refused vaccinations for their children were conducted. Qualitative data were used to develop a survey instrument including a series of scales measuring parental beliefs and attitudes about pediatric vaccination. The survey was administered via telephone to a random sample of 310 parents with children aged thirteen or under. Data describing the prevalence of vaccine questioning in the United States and the relationships between race/ethnicity, socioeconomic status, and mistrust and risk beliefs on parental questioning and refusal of vaccination are presented.

In addition, I provide an explanatory framework for vaccine questioning within the theoretical orientation of risk theories of modernity. I develop and test a conceptual model that examines the effects of risk assessment and engagement, mistrust or skepticism of

expert systems of knowledge, alternative medical orientation, social support, social status variables, and vaccine questioning and concern on parental vaccine practices. The dependent variable is a four category variable that incorporates both vaccine behaviors and perception of pressure to vaccinate.

Multinomial logistic regression results indicate that parental risk awareness, risk mastery, mistrust of science and medicine, and vaccine concerns are each significantly related to vaccine uptake behaviors. Results also show a conditional association between education and vaccine concerns. The positive effect of vaccine concerns on the odds of pressured vaccine acceptance and pressured vaccine postponement/refusal was significantly greater among respondents with higher education. There is similar evidence of a conditional association between minority status and vaccine concerns. Vaccine concerns increase the odds of pressured postponement-refusal and pressured acceptance more so among white respondents than among minority respondents. Public health and sociological implications of these findings are discussed.

INTRODUCTION

In conjunction with improved sanitation and other public health measures, mass vaccination efforts have proven highly efficacious in the reduction of vaccine-preventable diseases. Since the early quarter of the twentieth century, diseases such as smallpox, diphtheria, and pertussis (whooping cough) have shown declines of 97-100% (Centers for Disease Control and Prevention 1999a, 1998a). More recently, the middle part of the twentieth century saw dramatic declines in diseases such as tetanus (lockjaw), polio, measles, mumps, rubella (German measles); and the late 1980s showed reductions of *Haemophilus influenzae* (which can cause meningitis) and hepatitis B. For instance, while in 1969 there were 57,686 reported cases of rubella, in 1998 there were 364 cases, a decrease of 99.4% (CDC 1999a, 1998a). Declines in vaccine-preventable diseases, particularly the diseases of childhood, have been a public health triumph. Immunization campaigns and public education about vaccine preventable diseases, enforced by state vaccination mandates¹, have reduced some diseases to near total absence. As such, many people, particularly the parents of young children, have no recollection of the diseases they are told to immunize their children against. Against the backdrop of widely publicized controversies about possible adverse side effects attributed to vaccinations and investigations of vaccination safety and efficacy, a paradox has developed. A growing number of parents fear childhood immunizations more than they fear the diseases against which the immunizations are intended to protect their children (Bedford and Elliman 2000;

¹ Currently all 50 states and the District of Columbia have some immunization requirements for school aged children, and nearly all states have requirements for age-appropriate immunizations for children attending Head Start and day care.

Gellin, Maibach, and Marcuse 2000). Vaccinations, it seems, have become a “victim of their own success” (*Canadian Medical Association Journal* 2000: 801).

The purpose of this project is to explore contemporary American parents' questioning of and resistance to childhood immunization. In the event that a growing resistance to immunization could lead to future public health problems, a better understanding of parental decision-making processes and the dynamics of vaccine refusal will be required. From a sociological viewpoint, the issue of vaccine questioning highlights how the confluence of personal, cultural, and social structural dynamics influence parental decision making about their children's health care. Both vaccine acceptance and refusal raise questions about decision making, compliance with or questioning of traditional authority, collective benefit versus individual rights, and notions about the definition and management of risks in modernity. Data gathered from this study, therefore, will further our understandings about this growing concern in contemporary America and explore some of the social, structural, and cultural factors that may influence vaccine questioning.

The goals of this work are two fold. First, I seek to discover and describe the characteristics of parents who question and oppose pediatric immunization. One group of questioners are likely to have made alternative vaccine decisions, such as postponing vaccinations beyond the schedule recommended by physicians, or entirely foregoing specific vaccinations. I therefore examine how parents who have made alternative vaccination decisions are different from parents who accept vaccinations for their children. A second group of vaccine questioning parents is also likely to exist; I aim to identify the presence and characteristics of parents who have persistent vaccine-related concerns, but who have accepted vaccinations in a context where they perceive pressure to vaccinate from physicians or other authorities such as schools or daycare centers. If there are parents who would prefer not to vaccinate, but are unable to enact their decisions, these parents

may constitute a group of pressured acceptors who have different characteristics than both vaccine acceptors and those who have enacted alternative vaccine decisions. Thus, my first aim is descriptive. I will examine differences in the social and attitudinal characteristics of vaccinating and non-vaccinating parents and also explore the characteristics of pressured vaccine acceptors.

A second goal of this dissertation is to provide an explanatory context to parental decision making about vaccination within the framework of theories of risk in modernity. I assert that in contemporary American society parents are making health care decisions for their children within a context that is increasingly consistent with the contours of a "risk society." According to Giddens (1991, 1990), a feature of modern society is the decline in expert authority. As the judgments about risks made by experts and scientists are continually contested, as Giddens argues, lay people are drawn into personal risk assessment on the basis of their own calculations of acceptable risk. We live in a world that is increasingly more "risky" (Beck 1992); there are potential and actual global hazards that may be beyond intervention or cessation. Health threats from pollution, toxic waste, nuclear hazards, bioterrorism, and the transmission of zoonotic diseases are features of modern life. These potential threats of global life mean that individuals need to rely on the knowledge of expert risk assessors at the same time they have a growing recognition of the indeterminate sense of knowledge underpinning scientific assessments of risk (Adam, Beck, and Van Loon 2002). Expert knowledge is contested at the same time it is relied upon. Furthermore, because knowledge about risk is contested, there is the appearance that there is no one truth, only more legitimized versions of the truth. To this end, all knowledge about risk is political. In a risk society, such as our modern world, suspicion of expert knowledge and fears of unknown risks have translated into personal risk assessment

and management. This, I contend, is evidenced by the parents who are making alternative vaccine decisions for their children.

I hypothesize, therefore, that parental vaccine decisions are influenced in part by:

1) parents' general views concerning the presence of health-related risks and their ability to control or avoid them; and 2) mistrust or skepticism about "expert" knowledge, such as that derived from science and medicine, government, and corporations. My intent is not to try to measure whether or not we are in a risk society; rather, it is assumed that elements of a risk society are operational and shape the context in which parents make a host of decisions for their children, including vaccine related decisions. It is my intention to measure parental attitudes and perceptions about components of risk society, and to then determine if and how variations in parental perceptions of these constructs contributes to vaccine questioning or resistance. Assuming that there will be empirical support for these contentions, this work will contribute to the literature in medical sociology by uncovering and highlighting the socially constructed and mediated assessment of health and health related risks.

I hypothesize that additional factors influencing parents' decisions about their children's health care are parental friendship and kinship networks and the social support parents receive from significant others such as physicians. People typically surround themselves with people who share similar beliefs, and I expect that these networks will support and reinforce their beliefs about the risks and benefits of immunization. This contention is supported by Douglas (1986) and Douglas and Wildavsky (1982). In writing about risk assessment at the group level, Douglas and Wildavsky contend that groups of people identify risks on the basis of their social organization and the nature of their interactions in a wider political culture. Thus, this work explores the role of social networks and perceived support from both informal and professional relationships.

Finally, I contend that the social processes involved in parental vaccine decision making may not be the same for all members of society. I seek to examine how socioeconomic status characteristics such as education, income, minority status, and social and economic marginalization may moderate the relationships between parents' views about risk and their ability to avoid them and their skepticism about expert knowledge, on the one hand, and their vaccine related behaviors, on the other hand.

The work that follows first describes the phenomenon of parental questioning of and resistance to childhood vaccination. Then, I attempt to provide empirical support for a conceptual model that attempts to explain parental vaccine decisions.

CHAPTER 1

VACCINE CONCERNS: PARENTS' NEEDLING DOUBTS

Literature Review

Concerns about vaccinations have recently come back into American popular discourse.² In a modern context, controversial immunization issues have been discussed in European circles (particularly in Britain, as well as in British Commonwealth countries) for decades. This is reflective, in part, of the efforts of the British Health Education Authority, which has routinely surveyed public attitudes and understandings of vaccinations (Gellin, Maibach, and Marcuse 2000). Misunderstandings and attitudes averse to immunization have then been focused upon as public health education efforts. In addition, the cultural context was already sensitized to the dangers of cross-species disease transmission and biotechnology: from the last 1980s, Europe has been embroiled in controversy about the transmission to humans of bovine spongiform encephalopathy ('Mad Cow Disease') and Creutzfeldt-Jakobs disease through bovine products (*British Medical Journal* 2000). Certainly, it was no leap of reason to question vaccinations, many of which contain attenuated microorganisms found in animals or are cultured in substrates containing animal cells. In America the widespread questioning of vaccine safety has resurfaced only in recent years. While there was limited discussion of vaccine-related concerns in the 1980s, recent events have reinvigorated the debate.

² 'Anti-vaccination' arguments are not new. In fact, the parallel has been drawn between late 19th and early 20th century vaccine resistance in Britain and the US and the modern phenomenon discussed here. See Wolfe and Sharp (2002) and Greenberg (2000).

In the early 1980s, a group of American parents raised concerns about the adverse side effects, including high fever, brain inflammation, and seizures, associated with the bacteria contained in the whole-cell pertussis vaccine administered in the diphtheria, tetanus, and pertussis (DTP) vaccination. Several lawsuits were initiated against health care providers and vaccine manufacturers, and government concern grew that vaccine manufacturers would stop production due to the costs associated with liability. In addition, DTP uptake rates fell. Congress became involved, and in 1986 the National Childhood Vaccine Injury Act (NCVIA) (P.L. 99-660) was passed. This piece of legislation achieved several goals. First, the Act created the Vaccine Injury Compensation Program (VICP), which allowed for a no-fault alternative to law suits against vaccine manufacturers or providers (http://www.hrsa.gov/osp/vicp/fact_sheet.htm). Under the VICP, people able to prove an injury caused by a vaccine can file for compensation. Second, the Act provided a mechanism for systematic reporting of suspected vaccine-related adverse side effects. This system, the Vaccine Adverse Event Reporting System (VAERS), is co-sponsored by the CDC and FDA. Independent of the VICP, VAERS allows for data collection and surveillance of vaccine safety. Third, the Act instituted vaccine-related record keeping requirements by health care providers including the recording of vaccine lot numbers, providing parents with vaccine-related information about risks and benefits, and reporting of suspected side effects. Finally, the Act required further studies of the whole-cell pertussis vaccine. (An acellular pertussis vaccination was approved in 1991 for use in children aged 15 months to 7 years. In 1996 an acellular pertussis vaccine was approved for infants.)

Critics of the NCVIA contend that there are holes in the legislation. One is the voluntary nature of VAERS reporting. While parents, doctors, and vaccine manufacturers are encouraged to report suspected vaccine-related side effects, VAERS is a passive

surveillance system. It has the same problems as other passive surveillance systems including underreporting of suspected events, reporting of unconfirmed diagnoses, unsubstantiated temporal ordering of events, and lack of comparison groups in which reactions did not take place or rates of side effects in the general population (Zhou et al 2003). The process for compensation is also sharply criticized by claimants to the Vaccine Injury Compensation Program, as 72% of claims made for injuries occurring before 1988, while whole-cell pertussis vaccines were still used, have been denied (http://www.hrsa.gov/osp/vicp/monthly_stats_pre.htm). Another criticism of these programs is that the compensation program protects vaccine manufacturers; the 1986 legislation requires that vaccine injury claims filed after 1988 must be first filed through the VICP before civil litigation against vaccine manufacturers can be pursued. (If compensation is not awarded or is awarded and refused by the claimants, they then can pursue civil litigation.) Other parents criticize physicians who fail to provide vaccine information sheets to parents or to discuss risks and benefits associated with vaccinations, as they are required to do under the NCVIA. For these parents, informed consent before vaccination is a key issue.

As these programs went into effect, parental critiques started to emerge in the early 1990s. By the late 1990s, a new round of vaccine controversies surfaced. Several events, occurring within a short period of time, heightened concern in America. In 1999 the American Academy of Pediatrics and the US Public Health Service – concerned about cumulative mercury exposure and accumulation in children – requested that vaccine manufacturers remove the mercury-based preservative thimerosal from vaccines (Miller 1999). The CDC then pulled a rotavirus vaccine after reports of bowel obstruction in infants (CDC 1999b). In addition, reports circulated that the widely used MMR (measles, mumps and rubella) vaccine was linked to autism and pervasive developmental disorder

(Wakefield et al 1998). By 2000 there was concern that an early polio vaccine, given to 98 million Americans (Ready 2000), had been accidentally contaminated with the monkey virus SV40, which has been linked to certain cancers. As confusion ensued, many parents began to wonder which risk was greater: contracting a formerly common disease of which the contemporary risk has been stemmed, or developing adverse side effects from a vaccination intended to protect. In the case of the suspected link between the MMR vaccine and developmental disorders, new evidence indicates that there is not a causal association between the vaccine and disorder (Taylor et al 1999; Offit 2002; Stratton et al 2001; Taylor et al 2002; Immunization Safety Review Committee 2004). Doubt has been raised, however, and has not been leveled as controversy has continued. Vocal parents who were critical of the 1986 legislation and its programs were joined by parents who were concerned with new issues of vaccine safety.

It appears that the profusion of recent popular discourse on the topic of vaccine safety and efficacy is influencing the health care decisions that parents are making for their children. Coverage of vaccine issues has spanned newspapers, magazines, Internet, radio, and television outlets. These issues include concerns about possible links of vaccinations with neurological disorders, sudden infant death syndrome, cancer, immune system dysfunction and chronic diseases, developmental disorders, and autism. Previous surveys indicate recent increases in parental questions about vaccine safety. Data from the Centers for Disease Control's National Immunization Program (NIP) indicates that from 1999 to 2001, program managers of state immunization programs have reported more public inquiries about vaccine safety. In 2000, 70% reported an increase in parent questions about vaccine safety (CDC 2002). In 2001, 33% of program managers reported that parental concerns about vaccines had affected vaccination rates, up from 16% in 2000. These concerns have translated into action on the part of worried parents. Thirty-four percent

(34%) of program administrators reported increases in the number of persons claiming religious or philosophical exemptions to immunizations, up from 23% in 1999 and 16% in 2000 (CDC 2002). A 2000 survey reports that four out of five physicians experienced at least one incident of parental refusal to vaccinate, and two thirds of surveyed doctors indicated that parents were raising more concerns about vaccines than in the past (Freed et al 2004). While it is difficult to calculate the actual number of deliberately non-immunized children in the U.S., it is clear that parental vaccine questioning is increasing, and a growing minority of parents is choosing to postpone or forego immunizing their children.

Of the 11,000 babies born in the US every day, an estimated 8,700 will get the full series of immunizations recommended by the Centers for Disease Control and Prevention (Marwick 2000). Data from the CDC's 2002 National Immunization Survey estimates that approximately 79% of US children complete a series of 4 or more doses of DTaP, 3 polio doses, and at least 1 measles containing vaccine (referred to as the 4:3:1 series) (CDC 2002c). The question has often been asked why vaccine uptake is not complete (CDC, 1998b). Access to and cost of immunizations have been studied at some length (Minkowitz and Guyer 2000), particularly in looking at under- and uninsured children and minorities. For instance, insurance coverage and access to routine medical care are closely related to minority status. As of 1998, 29% of Latino children were uninsured. Similarly, 19% of African American children, and 15% of children of Asian or Pacific Island descent were without insurance, compared to 11% of white, non-Hispanic children (Brown, Ojeda, Wyn, and Levan 2000).³ With such high levels of lack of insurance and under-insurance, access to care is constricted, which can translate into differences in immunization rates as well as

³ The introduction of Children's Health Insurance Programs (CHIP), intended to increase insurance coverage for children in low-income families not qualifying for Medicaid, are reducing these figures.

disparities in growth tracking, diagnosis of developmental delays, as well as timely resolution of acute care health needs that may become chronic illnesses. For children under five, for instance, 1995-1996 figures from the National Health Interview Survey show that 5% of Caucasian and African American, and 8% of Asian and Pacific Islander and Latino children did not obtain the minimum of at least one annual visit to a primary care physician for a physical exam.⁴ There are clear differences in vaccination rates by race and ethnicity and social class. In 2002, 81.2 % of white children above the poverty line received the 4:3:1 series, compared to 71.6% of black and 76.5% of Hispanic children. For children under the poverty line, the figures are 73% for white, 69.3% for black, and 75% for Hispanic children (CDC 2002d).

Yet, despite access and cost issues, there will still be a portion of children who will not be fully immunized due to parental dissent. Parental dissent and non-compliance with vaccination has been studied more in developing nations as a part of vaccination campaign design and evaluation initiatives (Streefland, Chowdhury, and Ramos-Jiminez 1999), yet there is little empirical research into the patterns of parental compliance in the US that have recently developed. Furthermore, little is known about the characteristics of parents who make the choice against immunization (Gellin, Maibach, and Marcuse 2000). The bulk of what is known is based on clinical experience (Bedford and Elliman 2000) or theoretical speculation (Bradbury 1999), and is sometimes linked to the characteristics of clinicians, such as their training as allopathic, chiropractic, naturopathic, or homeopathic practitioners (Lee and Kemper 2000; Perrin and Kemper 2000).

The contention could be raised that since most parents choose to vaccinate, the issue of non-vaccination is rather minor. Admittedly, the percentage of all parents who

⁴ The figures are more striking for school aged children (6-17 years old): 8% of African American children 12% of Asian and Pacific Islander, 16% of Latino, and 18% of Native American, Native Alaskan, and 7% of white children did not have recommended visits.

withhold immunizations will be a small portion of all parents. Yet, there are dramatic consequences when the general immunity level in a community diminishes. Thus far, the success of immunizations rests on the principle of herd immunity: when the vast majority of individuals are immunized, there is little risk to those who are not immunized. In fact, high immunity levels in the general community allow some unvaccinated individuals to enjoy diminished risk of disease through decreased exposure without them having to submit to the risks of immunization. Yet, what happens when the overall immunity rate goes down? Because of their increased susceptibility, unvaccinated individuals can introduce disease into a community, and thereby threaten the health of other non-immunized persons or those who were vaccinated but were insufficiently protected. This was the case in Utah during a 1999 measles outbreak (Salmon, Haber, Gangarosa, Phillips, Smith and Chen 1999). Utah has a rate of exemption from immunization that is three times the national average. When the measles outbreak started, most of the infected individuals were non-immunized. But, the virus spread to people who had been immunized, but were under protected (due to immunity failure or vaccine failure) (Salmon et al 1999). Another recent example was a pertussis outbreak in an Iowa City elementary school, which affected 17% of the elementary school population (Pediatric Alert 2002). Children who received three of the recommended five vaccine doses were at a five-fold increased risk of contracting the illness, whereas full immunization showed 80% effectiveness. Among the factors contributing to the outbreak were incomplete immunization, insufficient protection with full immunization, and multiple sources of disease introduction. Thus, as herd immunity breaks down non-immunized individuals do pose a potential threat to the health of the overall community. A more complete understanding of the processes by which parents arrive at the decision not to immunize is of importance to public health education, a

general understanding of public sentiment in American society, and efforts at disease surveillance and monitoring.

In addition to the public health ramifications, the issue of vaccination choices underscores the tension between public policy and individual rights. On the whole, public health policy is largely utilitarian: the system of enforced vaccination mandates serves to impose upon everyone what is considered to be in the best interests of the whole – in this case, health promotion and prevention of disease and suffering. Yet, at the same time, the allowance of personal exemptions to vaccine mandates means that individuals are allowed to act in their own interests (or, more precisely in this case, to act according to what they determine are the best interests of their children). This encourages the idea that individuals are the best ones to make health care decisions for themselves, even if those decisions are at odds with public policy. Recent debates over state exemptions, the maintenance of herd immunity levels, and the provision of forced anthrax or smallpox vaccination in the event of a bioterrorist attack highlight the conflict between what is in the interest of all versus what is right for the individual.

While there are clear public health implications to the issue of vaccine refusal, the topic highlights and demonstrates several sociological issues. When parents are making decisions to not vaccinate their children, they are taking a stand against government mandates and the dictates of medicine. In a wired society where electronic access to information is abundant, awareness of the debates about childhood vaccinations may be in the consciousness of many parents of young children. But how parents evaluate and eventually come to believe in arguments for or against vaccination is not done in a social vacuum. Questioning of and/or rejection of medical recommendations and public health policies are certainly influenced by the parent's social location as an actor in a larger social structure where race, ethnicity, access to primary care, education, and income interact to

influence the success parents will have in raising questions, receiving satisfactory answers, and, ultimately, enacting their will for their children.

More broadly, the issue of social resistance to vaccination can be seen as evidence of a trend toward individual risk assessment and personal management of the risks associated with living in modern society. When the knowledge of expert systems has become contentious and the faith of laypeople in the certainties of sciences has diminished, individuals may become more likely to engage in personal management of risk. The weakening of institutional authority signaled by vaccine questioning and refusal may be revealing about modern social organization.

Vaccine Refusal: Theoretical Paradigms and Empirical Evidence

Streefland et al (1999) identified patterns of vaccine acceptance and the factors that influence it. Though most of their studies were concerned with patterns of acceptance in developing countries (India, Bangladesh, Ethiopia, Malawi, and the Philippines), many of their conclusions can still be applied to the US and other industrialized nations. High rates of vaccinations in the industrial west have been somewhat of a foregone conclusion. As such, research into patterns of noncompliance has not often involved western countries. This is one area in which the current research fills a gap in the existing literature. With what appears to be recent increase in dissension with vaccination recommendations and requirements, application of research findings from developing countries may aid our understanding of the developing trend towards vaccine rejection in the US.

In any culture, shared notions about immunizations will emerge when relatives and neighbors share exchanges of their vaccination experiences. These stories, combined with beliefs in the safety and efficacy of modern medicine, beliefs about disease in general, and perceptions of need for preventative health measures all contribute to what Streefland et al

call “local vaccine cultures.” When vaccination is widely accepted (as it has been in the US for much of the last century), vaccine supporting parents are interdependent – they support (and are supported by) their shared decision to vaccinate their children. Within the scope of this vaccination culture, it is difficult *not* to vaccinate. This would mean taking a stand against the norm, taking control of the health of one’s child, defending one’s decision against the claims of friends, relatives, and medical professionals, and opposing requirements that may make school enrollment more challenging. But, when this collective reinforcement and interdependence breaks down, more people may select to postpone or refuse to immunize their children. In short, the vaccine culture has changed.

This may be the result of broader cultural changes. Evidence from Pescosolido, Tuch, and Martin (2001) reveals that, in general, people’s attitudes towards physicians, the work they do, and their abilities to manage medical problems became more negative during the period of time from 1976 to 1998. Furthermore, whereas in 1976 there was some uncertainty in people’s feelings, by 1998 the ambivalence and uncertainty had crystallized into decidedly negative feelings. These sentiments do not relate directly to immunization beliefs, but may show that a broader social phenomenon of change in people’s attitudes can shape beliefs about specific medical procedures. Furthermore, in recent years, large scale corporate scandals at Enron, Health-South, and Worldcom have heightened American’s weariness about the claims in big business. Increased suspicion about corporate conflicts of interest and misdeeds may have spilled over into mistrust of pharmaco-medical corporations. If this is the case, parents may be more sensitized to how vaccine manufacturers, pharmaceutical companies, and the government may indeed make strange bedfellows. This, in turn, could influence their decision making about the health interventions their children will receive.

The idea of vaccine cultures needs to be examined in the context of American parents' vaccine decision making, and especially in regard to possible racial, ethnic, or class differences. This may become more salient in immigrant subcultures in the US, particularly if folk beliefs about disease etiology, treatment, and progression are prevalent (Pachter 1994). Indeed, cultural beliefs even shape notions about the benefit of disease and connections between bodies and souls (Fadiman 1998). Alternately, cultural change in notions about vaccination may be more prevalent amongst more highly educated parents or parents with greater financial means, as they may have the ability to seek out alternative care for their children. Regardless of the socioeconomic status of parents, I posit that interpersonal networks will serve as a key source of vaccine information and support for vaccine refusal. This research project investigates the role of local vaccine cultures through interviews conducted with parents who have made the decision not to vaccinate their children. The survey portion of the project also investigates the importance of social network support for vaccination.

Both the quantitative and qualitative portions of the research also probe the issue of parental mistrust and suspicion of medicine, science, government, and corporations. These four areas are treated as realms of expert knowledge. It is hypothesized that the extent to which parents express mistrust or concern about the claims of expert knowledge systems will affect their vaccine related concerns, and that these will influence the likelihood of parents making alternative vaccine decisions.

Active Demand vs. Pressured Acceptance

Nichter (1995) distinguishes between active demand for vaccinations and passive acceptance. Under the condition of active demand, the public sees the benefits of vaccination, and seeks it out. This group is the majority in the US. The high vaccine

coverage levels reported in the US support this.⁵ Evidence of active demand is also born out in empirical findings. Gellin et al's (2000) findings from a nationally representative survey show that the majority of parents surveyed (82.8%) responded that they planned to vaccinate their children in order to prevent disease. Clearly, these parents actively support vaccination (however uncertain or low the risk of the child contracting the illness) and perceive that the benefits outweigh the risks or cost associated with the immunization.

Contrary to active acceptance, passive acceptance (Nichter 1995) involves compliance not necessarily informed by an explicit choice to vaccinate, but rather compliance stemming from mandates or regulation. In the current research project, the concept of passive acceptance has been modified and renamed. I am interested in parents' experience of pressure, from physicians or daycare and schools, to vaccinate. External pressure on their decisions may be particularly important when parents have persistent questions about a vaccination, or when they would rather that their child not be vaccinated. In the present research I explore "pressured acceptance," which is vaccine compliance, despite persistent questions or concerns, acceded to following pressure from mandates or health care providers. Nichter's term "passive acceptance" implies that parental vaccine acceptance is passive to the extent that they are not actively seeking out vaccination for their children but do consent because of regulations. I have opted to rename Nichter's term to reflect the idea that parents are not passive; they may, in fact, be actively engaged in vaccine-related debates and controversies and struggling to make good decisions for their children, but find it difficult to enact these decisions in the face of pressure from mandates. Though intrinsically parents may not want to vaccinate their children, they may comply

⁵ In 2001, approximately 94% of American preschool children received three or more doses of diphtheria, tetanus, and pertussis vaccines (DTP or DTaP); 91% received one or more measles, mumps, and rubella vaccines (MMR); 90% received three or more polio vaccines; 93% received three or more *Haemophilus influenzae* type b (Hib) vaccine; and 89% received three or more doses of hepatitis B vaccines (CDC 2002).

because this is what they are told to do, e.g., in order to enroll the child in public school. Of interest to sociology is the notion that prevailing inequalities shape people's compliance, as weaker members of society conform to the suggestions and demands of elites (Streefland et al 1999). In the context of immunization programs in developing countries, Streefland and colleagues refer to landless peasants as an example of weaker members of society. In applying this theoretical reason for vaccine acceptance to the contemporary US, weaker members of society may be younger parents, members of lower socioeconomic groups, those with lower educational attainment, and racial and ethnic minorities, whose compliance to elites (medical professionals and school/daycare administrators) is shaped by their positions of relatively low power, and social and economic marginalization.

Pressured acceptance of immunization calls for closer examination. To the extent that parents experience pressure to vaccinate despite doubts or concerns they may have, these parents may represent the next group of parents opting their children out of vaccination. Indeed, parents pressured to vaccinate one child may opt out of vaccination for subsequent children. Future vaccination resistance may increase the number of partially immunized children, thereby lowering the rates of children receiving the full series of recommended vaccinations and further weakening herd immunity.

One of the research questions posed in this work examines whether parents experience pressure to vaccinate, even when they have questions or concerns about immunization. Racial and ethnic minorities and parents with lower incomes or education may be more likely to be pressured acceptors of vaccinations. This may be because of direct pressure placed on these parents by health care providers, or because of differential access to and inconsistencies in health care. For examples, Hispanic Americans are twice as likely as whites to not have a usual source of primary care (Zuvekas and Weinick 1999), and minority children are especially likely to lack a consistent health care provider (Brown,

Ojeda, Wyn, and Levan 2000; Newacheck, Hughes, and Stoddard 1996; Weinick and Krauss 2000). When parents have a difficult time accessing reliable, consistent care from providers they know and can develop a relationship with, they may not have their questions about vaccinations answered and they may then feel they consented to medical interventions about which they had reservations. Conversely, parents running up against barriers to obtaining health care for their children may be more apt to accept physicians' recommendations without as many questions precisely because health care is the commodity they are seeking but otherwise lacking. Data from the present study could help inform public health officials about the perceptions and circumstances of groups who feel disenfranchised from the public health system, and consequently aid in shaping education efforts.

Figure 1.1 presents a typology of the four groups resulting from the combination of vaccine uptake behavior and the perception of pressure.

		Was child vaccinated?	
		Yes	No
Were parents pressured by doctors, schools, and/or daycare providers?	Not Pressured	Active Demand (Majority of American parents)	Non-Pressured Postponement/Refusal
	Pressured	Pressured Acceptance (Parents who feel pressure to vaccinate despite their questions or who would choose not to vaccinate but have difficulty enacting their decision in the face of pressure.)	Pressured Postponement/Refusal

Figure 1.1 Pressured and Non-Pressured Acceptance vs. Postponement/Refusal

Gellin et al (2000) cite that that while most parents surveyed (82.8%) supported vaccination as a rational means of disease prevention, 7.8% responded that they would accept vaccinations for their children because of state requirements in order to have their children admitted into school. Further, Gellin et al's results support the notion that marginalized members of society are more likely to comply with mandates of elites, when education and race are taken as measures of social position. Respondents with a high school education were more likely (9.3%) to regard government mandates as a principle reason to immunize than were those with some college education (8.4%) or those with a college degree (6.0%).

While these differences are not large, the differences in percentages are greater when race is taken as a measure of social position. African American respondents were more likely (16.2%) to consider requirements as a principle motivation to immunize than were whites (6.4%) or Hispanics (7.1%). Given the nearly ten percentage point difference between blacks and whites, the implications of this finding are substantively significant. Clearly, African Americans are more swayed into immunizing their children because of mandates. (We are unable to conclude, however, if absent these requirements, these parents would choose not to immunize.)

Gellin et al's study does not allow for any explanations to be made for this finding, but one could make reasonable hypotheses in line with sociological theories of conflict. Given the exploitative and oppressive history of race relations in the US, I hypothesize that African Americans will be more mistrustful of governmentally mandated medicine, especially vaccinations. The legacy of the Tuskegee syphilis experiment set the stage for African American's general distrust of medicine and public health efforts (Thomas and Quinn 1991; Jones 1993). Racial politics within medicine are still highly charged, and are evident in racialized debates from HIV and AIDS (Thomas and Quinn 1991) and genetic

engineering (Wailoo 2001). In the white dominated medical field, African Americans may feel skeptical of immunizations, especially when they are promoted by non-minority physicians and are mandated by the same government that engaged in deliberate and covert racist experimentation for forty years. Thus, while not eager to immunize their children for other reasons, mandates to immunize in order to get their children into school may be a principle force behind black parents' decision to immunize. This is explored in this dissertation.

Diversity in Reasons for Vaccine Refusal

Whereas most parents will accept vaccinations for their children, either as the result of external pressure or their own priorities, in contrast are parents who do not have their children immunized. For some parents, non-immunization stems not from a lack of desire to immunize, but from conflicting demands on their time, energy, or resources that in essence create roadblocks to vaccination (Streefland et al 1999). This group of parents who experience obstacles to immunization is in some ways the inverse of passive acceptors; these are passive rejectors. The very same marginalized status positions that make it difficult for some parents to reject immunizations they do not want their children to receive may be the same status positions that preclude vaccine-seeking parents from vaccinating. For example, low income or working poor parents with restricted access to medical care may find it difficult to get their children immunized. Many poor neighborhoods, particularly in urban areas, are served by community health centers. These clinics are more likely to be under-funded and under-staffed, with long appointment waiting times and strains on record keeping and tracking of patients' vaccine status. These conditions are caused by structural factors that perpetuate inequality. They are outside the control of parents, and mean that despite parental wishes, their kids may fall through the cracks. The

group of parents wanting to immunize but meeting structural impediments will not be a focus of this study.

The group of parents of non-immunized children who are the focus of the qualitative portion of this study is the segment of the population who have access to health care and whose non-immunization stems from deliberate postponement or refusal. (Refusal to vaccinate may mean that parents are entirely foregoing vaccinations for their children, or that they have created alternative vaccination practices for their children, such as separating out combination vaccines like the MMR or altering the recommended vaccination schedule. For the purposes of this discussion, both postponing and foregoing are treated as similar constructs, though they could be empirically treated as distinct.) My past research and preliminary data indicated different motivations and situational contexts leading to vaccine non-compliance. This supports contentions found in the literature. According to Streefland et al, for instance, resistance to state mandates, mistrust of medicine (including fears of vaccine safety and concerns about efficacy), or questioning the need for vaccinations when taken in context with other beliefs (religion or alternative medical orientation, specifically) affects vaccination refusal (Streefland et al 1999). I speculate that all three of these influences are operating in the recently developing American context of anti-vaccination sentiment.

Resistance to mandates Resistance to vaccinations may be a micro expression of a political stance, calling on the state to recognize individuals' freedom to refuse medical intervention into individual bodies, and the rights of parents to make decisions for their children in accordance with their beliefs. The limited available empirical evidence supports this theoretical reason for vaccine non-acceptance. Results from Gellin et al's (2000) survey show that one-fifth of respondents were opposed to government mandates on immunization. Eighteen percent state that their opposition to mandates was because

mandates go against parents' freedom of choice. This finding is similar to statements made by parents in preliminary interviews I conducted, yet qualitative findings appear to provide a more nuanced understanding of why curtailments of parental choice were troublesome. For instance, some parents expressed the belief that the "one-size-fits-all" health recommendation of mandatory vaccination policy was faulty and did not allow parents to make health care decisions based on their children's medical and family histories. Another parent raised her objection to mandated vaccination on the basis of what she called "freedom from intervention." She explained, "I mean, my children are perfectly healthy, and I'm told I *have* to put something in them that could make them sick. They say that vaccinations are about prevention, but I call it intervention, and I want freedom from intervention."

Mistrust of expert knowledge. As Streefland et al (1999) write, the perception that vaccines in themselves pose significant risks reflects "growing mistrust in competence of experts and efficacy of technology, incited by the press and specific interest groups" (pp. 1716). Since the 1970s there is a growing mistrust of physicians and medical profession, which is seen as "a dominating, monopolizing, self-interested force" (Starr 1982: 392). As discussed above Pescosolido, Tuch, and Martin (2001) found that people's attitudes towards physicians, the work they do, and their abilities to manage medical problems are more decidedly negative than in the past.

Increasingly, Americans realize that science is not a value neutral endeavor, and that politics and medicine are often closely allied. Some are fearful that political decisions influence immunization development and policy (Ready 2000). An example of this can be seen in debates before the November 2002 approval by the Senate of the Homeland Security Bill (H.R.5710). Concern was raised about sections of the bill providing liability exemptions shielding pharmaceutical manufacturers from vaccine injury lawsuits. Mistrust

in expert knowledge is also related to media coverage and press attention, as Streefland et al (1999) proposed. Specifically, increased media attention to vaccine adverse side effects influences parental decisions and increases vaccine rejections. For example, after a reported link between the MMR vaccine and autism in February 1998 (Wakefield et al 1998), MMR vaccine uptake in the UK fell from 90.4% (1997) to 87.6% in 1998 (Bradbury 1999). Despite the lack of any clear causal connection between autism and MMR (Bradbury 1999; Taylor et al 1999; Stratton, Gable, Shetty, and McCormick 2001; Offit 2002; Taylor et al 2002; Immunization Safety Review Committee 2004), the association between childhood vaccinations and deleterious long term consequences persists.

Questioning the need for vaccination when taken into context with other beliefs

Streefland et al (1999) write that “unlike the resistance based on religious ideas like ‘if we fall it is the will of god’, the ‘alternative expressions’ of resistance to vaccination are directed at core assumptions about the bio-medical systems itself” (pp. 1711).

Furthermore, they assert that followers of ‘alternative’ or ‘New Age’ philosophies who resist vaccination are generally well educated parents who are convinced vaccination may impair the immune system, produce long-term consequences or unknown side-effects, or generally be unsafe. Thus, those who resist vaccinations for their children are likely to be the very same people who have access to scientific and medical debates about risk. In fact, findings from 1998 data reveal that people from more powerful social groups, specifically those with higher incomes and more years of education, reported less confidence in physicians (Pescosolido et al 2001). Those who formerly would have accepted the knowledge of science have now come to question it, sometimes in favor or seemingly “non-rational” alternative discourses.

An intriguing aspect of the Gellin et al study is their attempt to address differences in vaccine knowledge and beliefs between parents who hold conventional and alternative

medical views. Though their classification of parents' medical orientation as "alternative" is problematic,⁶ they did find significant differences between those with traditional and alternative medical views. For instance, respondents with traditional medical orientations were more likely (89.4%) than those with alternative medical orientation (75.5%) to view immunization as extremely important. What is more, parents with an alternative orientation were more likely (24.9%) to opt out of at least one immunization than were those inclined towards a traditional orientation (11.2%). In terms of opting out of vaccinations, college graduates were more likely (16.9%) to reject at least one vaccination than were parents with a high school education (10.7%). From this study we cannot make any causal connection between education and medical orientation. We can, however, hypothesize that higher educational level would generally increase one's comfort and ability to express skepticism about the need for vaccinations and medical protocol in general. This may be the reason for the positive relationship between education and rejection of at least one vaccine reported in Gellin et al.

We can also extend this line of thinking to assert that openness to alternative medical therapies might come with higher educational levels. This supports Streefland et al's contention that 'New Age' followers resisting vaccination are well-educated parents who question vaccine safety, side effects, and efficacy. Certainly, the practice of alternative therapies carries with it a steep price tag, as therapies such as homeopathy, naturopathy, and acupuncture are not likely to be covered by insurance plans, and are usually more expensive than comparable visits to 'conventional' medical practitioners (Lee

⁶ Parents were classified as having an alternative medical orientation if they used any alternative therapy during the last year, and they indicated that they use either alternative or alternative and conventional therapies to treat their medical problems. As parents were referring to their own medical care, there is no assurance that parents would necessarily have the same orientation towards health care for their children as they do for themselves. The survey outlined below seeks to confirm the findings of the Gellin et al study, but directly asks whether parents have sought complimentary or alternative care for their children.

and Kemper 2000; Perrin and Kemper 2000). Thus, the idea that educated parents are more open to alternative medicine has merit.

A counterpoint to this contention could be that wealthier or more highly educated parents may be more aware of the consequences of globalization, and may be more willing to accept vaccinations for their children. Parents who travel with their children or who are eager for their children to travel may comprise another category of skeptical acceptors. Despite concerns or questions about the potential hazards associated with vaccinations, parents with an awareness of the consequences of globalization and international disease transmission risks may consent to vaccination in the face of potentially increased disease contraction risk.

The Role of Alternative Medicine in Patient Rejection of Vaccinations

The use of alternative and complementary medicine appears as a recurring theme in preliminary interviews conducted with non-immunizing parents. Most parents stated that they use "holistic", "natural", or "herbal" medical remedies, and many said they preferentially use these types of remedies before medical pharmaceuticals. Nearly all parents had sought medical care for their children from chiropractors, homeopaths, or naturopaths. As alternative health practitioners continue to grow in number and their methods gain popularity, as is the current trend (Lee and Kemper 2000; Perrin and Kemper 2000), then we must develop a more comprehensive understanding of the role alternative health practitioners play in parents' decisions to postpone or forego vaccination. Examining evidence on the three most popular pediatric alternative medicine areas (chiropractic, homeopathy, and naturopathy), a clear picture begins to develop in which vaccination recommendations from these practitioners may be less likely.

Chiropractic Medicine

Chiropractors are the number one alternative therapy to which children are brought (Spigelblatt et al 1994). In 1998 over one billion dollars was spent on chiropractic care for children; that was one fourth of all chiropractic care purchased that year (Perrin and Kemper 2000). Perrin and Kemper report that while 79% of chiropractors have specialty training in pediatric techniques, only 30% actively recommend immunizations for their pediatric patients. A full 70% of Massachusetts chiropractors surveyed recommend herbal remedies and food supplements, and many dispense herbs as part of their practices—clearly indicating a more alternative or complimentary orientation to medicine (Lee and Kemper 2000). If this is so, then we may be able to expect that parents who take their children to chiropractic care are more likely to be open to alternative remedies and may be less likely to immunize. Use of alternative medicine is also related to socioeconomic status. In the case of chiropractic care, most visits are paid out of pocket. Lee, Li, and, Kemper (2000), for instance, found that 49% of chiropractic fees for pediatric visits were covered by insurance. The group of parents taking their children for chiropractic care, therefore, is not likely to be poor. As income and education are related, we could hypothesize that parents with the means to pay for chiropractic care are likely to have a higher education. Spigelblatt et al's (1994) finding that children in alternative medical care have better educated mothers supports this assertion. Thus, educational attainment, income, and medical orientation may interact to produce a parent more skeptical of immunizations, and one who has the means to seek out a practitioner who may not recommend immunization.

Homeopathy and Naturopathy

In a survey of the practice and practitioner characteristics of homeopathic and naturopathic practitioners in Massachusetts, Lee and Kemper (2000) found that nearly all the practices surveyed reported treating children. Less than half of these practitioners,

however, reported having any pediatric training. Homeopaths and naturopaths, respectively, are the second and third fastest growing complementary practitioners treating children. Of the 42 homeopathic practitioners surveyed by Lee and Kemper, only eight recommend vaccinations (less than 20%). Only three of twenty-three naturopathic practitioners recommend vaccinations (13%). On the other end of the spectrum, two homeopaths and one naturopath claimed to oppose vaccinations. In between recommending vaccinations and actively opposing them, however, is a big gray area into which many complementary practitioners fall. The remaining 32 homeopaths and 19 naturopaths surveyed by Lee and Kemper either make no recommendation about immunizations or they simply didn't answer the survey question—which, we do not know. Evidence about homeopaths and naturopaths in the UK and Australia might give an indication of the general sentiment of these practitioners. Lee and Kemper report that 83% of Australian homeopaths and 70% of British homeopaths do not recommend immunizations. Similar findings are reported for naturopaths. The reasons are varied: some have an antipathy towards conventional medicine, some believe that vaccinations are harmful, and still others believe their own treatments and practices to be more protective and natural. At the level of professional organizations there is also widespread rejection of immunizations. The Society for Homeopaths, Institute of Complementary Medicine, and Homeopathic Medical Association are major professional organizations—none of these organizations support immunizations (Morrell 2000).

Whether these alternative practitioners support immunizations or not, what is of concern is that silence about immunizations in the form of no recommendation may be a message to parents. The influence of alternative practitioners must be a part of any effort to understand parental immunization decisions. Gellin et al (2000) report that 84% of parents claim to get their medical knowledge from health care practitioners, and some of these

practitioners are likely to be alternative therapists who may or may not support immunization. Furthermore, since naturopaths and homeopaths spend longer periods of time with patients per session (when contrasted with conventional medical practitioners), the message about immunizations they put forth may be even more salient and have a greater impact.

Not only may alternative practitioners be silent about immunization, but also there is concern about what they would say if they were to provide information to parents. In naturopathic and homeopathic circles there exists the notion that childhood diseases like mumps, measles, and chicken pox are harmless, natural and/or no longer a threat (Pinker 2000). Pinker also reports that some parents have been told by alternative practitioners that because vaccines contain attenuated strains of viruses, children can contract the disease which the vaccine is intended to prevent. Such misinformation echoes Gellin et al's (2000) finding that parents with an alternative medical orientation have more misconceptions about vaccinations and are less likely to believe in evidence about safety and efficacy than are parents with a more conventional medical view. These implications become all the more important as alternative medicine becomes more popular.

In this study I examine how parents use of and views of alternative and complimentary medicine are related to vaccination behaviors.

Vaccination Information Sources

The recent changes in American vaccination culture (Streefland et al 1999) are at least partially attributable to the influence of the media, which makes widespread the stories of people's vaccine experiences. As stated above, Bradbury (1999) contends that public perceptions of vaccinations do influence vaccination uptake rates, as evidenced by the drop in MMR vaccinations in the UK following a news story connecting the vaccine

with autism. Despite the veracity of the information, the adverse reporting will play a role in some parents' decision not to vaccinate. Therefore, another piece in the puzzle of how parents make immunization decisions—particularly the decision not to vaccinate—is related to the content and quality of information parents have available to them.

Gellin et al (2000) surveyed parents about the sources from which parents derive their medical information. Media venues played a significant role as sources of information. Eighteen percent of parents surveyed reported receiving information from newspapers and magazines, and seven percent cited the Internet as an informational source. A cursory look at print media reveals an interesting trend. During 1999, both *Newsweek* (Kalb and Foote 1999) and *Time* (Jarnoff 1999) magazines carried stories about suspicion of vaccine related adverse events. Both mentioned the link between autism and the MMR vaccine, yet neither mentioned that there was no conclusive causal link established between the two events. Nor did they write that there is a possibly spurious relationship between the MMR vaccine and autism. The time frame in which the MMR vaccine is given (between 12 and 15 months of age) is concurrent with the time at which parents are likely to notice developmental delays as children begin to walk and talk. The *Time* article goes further: it cites the National Vaccine Information Center (NVIC) as a source of information for parents to turn to. Calling the NVIC a 'clearinghouse' for vaccine related information, the article does not state that the center and its website have been widely criticized for being anti-vaccination.

Sibbald (1999), in an article reviewing Internet sites promoting vaccination information, finds that most websites offer false, unclear, or untrue information about immunization safety, risks, and efficacy. While there are credible websites available, parents may have a hard time sifting and sorting through the inaccurate information offered on official looking websites. This is echoed by Gellin et al's finding that while parents are

able to recognize sources of credible information on the Web, they tended to identify as credible a source that did not even exist. Parents were asked to give credibility ratings for the Centers for Disease Control and Prevention and American Academy of Pediatrics (AAP) websites, along with the fictitious organization the 'National Resource Center for Immunization Information.' Parents gave the CDC and AAP sites credibility ratings of 8.5 and 8.4 on a ten-point scale. Yet, they gave the fictitious organization a credibility rating of 7.8. This finding indicates that many parents may not have an awareness of organizations offering scientifically sound information about immunizations. With the proliferation of official sounding sites on the web offering vaccination information (Sibbald 1999), parents might not be getting reliable information when this is what they are seeking. Adding to the difficulty is the interlinking among websites that may oppose or be skeptical about immunizations. Wolfe, Sharp, and Lipsky (2002), in a systematic evaluation of 'anti-vaccination' websites, found that all of the sites they reviewed contained links to other sites presenting information averse to immunization.

Wolfe, Shape, and Lipsky (2002) report that 'anti-vaccination' websites express a range of concerns over vaccination safety that appear to be related to mistrust of medicine. For instance, all of the sites reviewed by Wolfe, Sharp, and Lipsky reported that vaccines cause illnesses of unknown origin, 95% reported that vaccines are related to lowered immune functioning, and 91% that vaccination policy is motivated by profit. Further, these websites rely heavily on emotional appeals. Fifty-five percent of sites presented stories of children who had been allegedly killed by vaccines (Wolfe, Sharp, and Lipsky 2002). The "gut level appeal" (Leask, Chapman, and Hawe 2000) at which some anti-vaccine related messages in print and electronic media operate should not be overlooked. Leask, Chapman, and Hawe's research into anti-vaccine media coverage and information shows that "manifest claims about vaccines being dangerous and ineffective tend to be located

under a canopy of more general discourses about cover up and conspiracy, manipulation by venal private enterprise interests, governments with totalitarian agendas, and the back to nature idyll” (109), all of which are likely to elicit emotional reactions. These trends can be seen on the National Vaccine Information Center (NVIC) website that has been cited in popular media coverage for several years.

The NVIC was founded to oppose mandatory vaccination, broaden state immunization exemptions, and lobby for the establishment of legislation requiring compensation to victims of vaccine adverse reactions. Since its founding in 1982, the NVIC has been a powerful lobbying organization, bringing vaccination safety issues to the federal government level. Barbara Loe Fisher, the NVIC founder, has served on the vaccine advisory committees associated with the National Childhood Vaccine Injury Act of 1986 and Institute of Medicine forums on vaccine safety issues. The NVIC and Fisher have been featured in a multitude of media outlets, including *CBS News*, *The Diane Rehm Show* (on National Public Radio), CNN and the *New York Times Magazine*. While the NVIC promotes itself as pro-information, supportive of informed vaccine decisions, and denies that its message is in any way 'anti-vaccination,' it is hard to deny the emotional appeal of its website. Part of the site homepage is clearly aimed at an emotional level, featuring four pictures of children affected by adverse side effects from immunizations. The individual pages for these children continue the emotional appeal, detailing how one child ended up on a respirator after a vaccine reaction, another was paralyzed from the chest down, and how two infants died.

The NVIC website offers many links to alternative medicine websites, personal injury lawyers who deal with vaccine adverse reaction cases, and sites offering help in crafting a case for legal exemption from state vaccine requirements. It does not, however, offer easily-found links to the Centers for Disease Control or American Academy of

Pediatrics websites. These links are embedded in other pages under the title "pro-vaccine." As a clearinghouse for vaccine information, as it purports to be, the NVIC has been perceived as and criticized for being more of a clearinghouse for anti-vaccination information. This is common, writes Sibbald (1999): sites will often discuss the risks of vaccination, but not mention the risks of not vaccinating. "When it comes to a volatile issue like immunization, the proliferation of questionable websites is truly disheartening. In fact, parents who surf the Web for information on immunization will be offered more anti-immunization propaganda than medically verifiable information" (736). Parents may use this information to make decisions about their children's vaccination status. Evidence from Meszaros et al (1996) on the cognitive processes of parents deciding whether to vaccinate their children against pertussis indicates that once parents have an emotional and cognitive stance against vaccination, the presentation of factual information about risks and benefits of vaccination can further enforce parents commitment to their vaccine rejection decision. The integration of the role of media information and Internet material in this process needs further attention. In the present work I examine if there are differences between vaccine accepting and postponing/foregoing parents in the sources of vaccine information on which they rely.

Risk and Resistance: A Theoretical Framework

In order to elucidate a theoretical framework for the emergence of parental resistance to childhood immunization, I now turn to an overview of Ulrich Beck's theory of the risk society. As a sociological theory, Beck's theory has some inherent problems. For instance, when judged against the criteria of sociological theory, it is flawed by its lack of clearly delineated and testable propositions. It is also concerned with the political implications of the social phenomena of modernity, and overtly promotes the project of the

social sciences as a manufacturer of social change. Nevertheless, by capturing many of the dimensions of the trend of immunization questioning and resistance, Beck's social theory seems particularly useful. The aim of this section is to outline Beck's framework and apply it to the specifics of immunization resistance. It is my intention in the second part of this research project to identify how parental perceptions of and attitudes about elements of a risk society vary. I then measure if and how variation in these perceptions and attitudes influences parental questioning of and resistance to vaccination.

Beck's framework focuses on the processes of modernity. Vaccines themselves are a product of modernity. They are a by-product of the rationality and reliance on science that have become predominant in the beliefs of western societies since the Industrial Revolution. But what is happening in the phenomenon of vaccine resistance can be seen as a backlash against the hegemony of science: in some ways the freedom *through* science that was once an attractive part of the project of modernity has given way to yearning for freedom *from* science and the powerful interjections and interruptions into human life it has come to mean.⁷ We never can be free of all science – the juggernaut is moving. But, we can, according to Beck, attempt to decrease the depth to which it pervades our lives. "We are therefore concerned no longer exclusively with making nature useful, or with releasing mankind from traditional constraint, but also and essentially with problems resulting from techno-economic developments itself" (Beck 1992: 19). (The project of taking on these problems is not universal, however. The same inequalities that exist in industrial society plague risk societies, and only those at the top of the hierarchy are likely to assume the

⁷ Yearning for freedom from science is manifest in a host of phenomena, which themselves are reliant, at least in part, on science. For instance, discussions of alternative medicines and sustainable energy technologies recognize the interjections of mainstream science into people's lives and people's reliance on science. At the same time, they aim to offer a way for people to free themselves from conventional sciences and technologies.

project of addressing its difficulties.) In attempting to explain this phenomenon, Beck's conception of the risk society seems particularly applicable.⁸

Whereas modern industrial society was about the distribution of goods and materials, risk society is about the distribution of "bads," dangers and possible calamities created by the interaction of industry and science. The conditions of modern life involve an inordinate amount of risk taking, in ways that are different from the risks taken by individuals in previous epochs. Risks are not new, but the types of risks are: early eras saw personal risks, whereas now our risks are becoming more global. Hunter and gatherers faced incredible risk to their lives – behind the next rock loomed the potential for a couching lion; but if the lion pounced, the risk of death was limited to those caught in its claws. Explorers and fishermen faced death every time their ships went to sea. Yet, their actions did not pose a threat to groups beyond those immediately involved. (There were collateral risks, such as the increased likelihood of starvation of the group if the catch or hunt was not successful; nevertheless, these risks are not the same as the immediate dangers that threatened those at sea or out hunting.) "In that earlier period, the word 'risk' had a note of bravery and adventure, not the threat of self-destruction of all life on Earth" (Beck 1992: 21).

Now, however, the consequences of risks are much more widespread, in large part because of the ways in which human beings have changed nature. Human cultures have fundamentally altered nature – the hole in the ozone layer, pollution, nuclear contamination, and antibiotic resistant bacteria are evidence of this. According to Beck, we can no longer talk about human culture and nature as distinguishable entities, especially as nature has been forever altered by the scientific "progress" of modernity. Contemporary

⁸ In what follows, only the explanatory portion of the theory is applied. This leaves out the latter parts of the theory concerned with the emancipatory and proscriptive projects of how modern societies should proceed politically.

risks, unlike those faced by previous generations, are not time or space-bound. They have the power to affect future generations and the potential to cross national boundaries. Furthermore, hazards in a risk society are often neither visible nor perceptible to those they threaten. Ironically, the only way to determine the hazard is through techniques of science – experiments, measurement instruments, etc. None of us know if the vegetables we eat are contaminated with carcinogenic pesticides or *E. coli* bacteria. If they are, we might develop cancer in fifty years or dysentery tomorrow. Further, we are not the only ones influenced by this – people all over the world may consume foods grown and processed in the same ways. Even those who do not consume the foods directly may be affected by the carcinogens, as babies nurse from their mothers or water run-off spills into the sea. People living around Three Mile Island may have had their genes altered by the nuclear contamination to which they were exposed, but their children may be the ones to inherit the legacy. Modern risks can transcend location and time, and thus they are different from risks of the past.

To Beck, the conditions of modernity⁹ have brought about unprecedented changes in traditional institutions, including specialized realms of knowledge. Beck contends that the traditional boundaries of knowledge are eroding. Because of this the certainties of calculable risks are diminishing. Paradoxically, these very risks are generated by the processes of modernization that attempt to control and even eliminate risks. This is exemplified by immunizations – science devised methods of stimulating immunity to protect against disfiguring and fatal diseases. Health was enhanced through technology. Risks were diminished, as is evidenced by the dramatic success of vaccination campaigns. Put differently, "In the past, the hazards could be traced back to an *undersupply* of hygienic

⁹ Giddens (1990, 1991) refers to this more specifically as "late modernity" and "radicalized modernity." What is important to note, however, is that Beck's risk society develops as a result of industrial society, and is not necessarily a break from it.

technology. Today they have their basis in an industrial *overproduction*" [emphasis original] (Beck 1992: 21).

In late modernity, with the increase in knowledge about the physical world and increasingly clever ways to intervene in it, there is recognition that models based on the natural world may not be completely applicable to risks created by human beings through our interventions in the natural order. According to Beck, the definitions of harm and danger we receive from experts are based on laboratory models or studies of the natural world. Formulas of risk are calculated according to how things *should* operate in theory, but these models might not hold in the non-theoretical world. Furthermore, the definitions of risk obscure political, social, and cultural meanings of 'risk.' Beck offers an example. Two men each have two apples. One man eats both his apples; the other man eats nothing. *On average*, each man has eaten one apple. Is the theoretical model of average risk from the apples a good match with the reality, especially when the theoretical model does not account for diversity of experience? What about variation that is due to socially unequal positions? Furthermore, how is the risk from multiple exposures accounted for by the model? According to Beck, most "scientific" assessments of risk are not valid approximations of actual risk because they ignore the complexity of the social world. "In other words, the insignificancies can add up quite significantly" (Beck 1992: 26).

In addition to the poor capability of science to accurately assess 'real life' risk, expert knowledge has other problems in a risk society. Conflicting claims of "experts" have become louder than the unified voices of scientific accord. We cannot, according to Beck, solely rely on expert knowledge any longer. Scientific viewpoints and claims come from groups and individuals with varied interests, which shape their definitions of risk. Often, the interests are hard to discover and disentangle. Beck sites the examples of the expert knowledge of scientists working for Union Carbide in Bhopal, India; nuclear

scientists at Chernobyl; and the government experts in Villa Parisi, Brazil. In each case, the expert knowledge systems assured the public of minimal risk. The results were catastrophe.

Furthermore, whereas the calculation and management of risks were once the tasks of professionals, now every person in the world is involved in having to manage potential risks. Nearly every act and decision has the potential to involve risk assessment. What food to eat, whether to exercise outdoors on a smoggy day, what roads to travel, where to take vacation – all these decisions are fraught with risk assessments. At best, we have some information upon which to make an informed decision, but even when people take into account the advice of experts, their knowledge is only more or less factually based. It still cannot tell us what the acceptable level of risk is, or if we should take it. In a risk society, risk becomes individualized: each person has the burden of risk assessment thrust upon him or her. As a result, "people themselves become small, private, alternative experts in the risk of modernization" (Beck 1992: 61).

As risk society is a historical period of modernity developed from the conditions of industrial society and not separate from it, we can expect that many of the prevailing inequalities of the class system of industrial capitalism will be found in risk societies. Class and risk are inversely related: whereas wealth accumulates at the top, risks accumulate at the bottom, and those with the most resources (education, power, wealth, and income, for instance) can "purchase safety and freedom from risk" (Beck 1992: 35). This holds true not only through social filtering (where environmental hazards are less likely to be found in wealth neighborhoods, for example), but also in the actively exercised capabilities of individuals in certain strata to avoid some risks. The prices of organic produce and free range eggs and chickens are an example of this. While everyone may want to avoid exposure to pesticides, not all can afford to. But, Beck also describes a

"boomerang effect": while the risks avoided by the wealthy can further perpetuate existing inequalities, the effects are likely to eventually come back on the wealthy. The chemical plants located in developing countries or the trash incinerator located in a poor section of the city are going to contaminate the food chain that the poor and wealthy eat from, and the air all people breathe, regardless of income.

Not only the knowledge of experts reveals conflicts. Despite their skepticism and sense of alienation from the institutions of traditional knowledge, actors in a risk society must rely on these institutions because "science is one of the causes, the medium of definition, and the source of solutions to risks" (Beck 1992: 155). But, people are not helpless in the face of science: they can fashion what Beck calls the *scientization of the protest against science*.¹⁰ In the process of developing a critique, however, conflicts between private decisions and public assessments of risk are often revealed. These critiques often highlight conflicts of interests amongst actors in the general public. For instance, some parents may want their children under the care of a pediatrician, but question some of the recommended treatments the physician suggests. In some aspects these parents defer to medical/scientific assertions, while in others they reject them.

Risk Society and Vaccination Questioning

The phenomenon of vaccine questioning and refusal fits Beck's descriptions of what can occur in a risk society. First, the risks that stem from vaccination *and* the alternative of non-compliance are unlike risks in previous eras. Vaccines are a product of modernity, and the proliferation of new vaccines could in fact be seen as an oversupply of

¹⁰This is part of Beck's outline of reflexive modernization, in which a critique of science relies, at least in part, on the techniques and definitions of science. The result is that the internal contradictions and strife within the scientific community are made public, and as Beck writes, science has to reveal all its limitations and "birth defects" (pp. 161). "In short, *in the course of the scientization of protest against science, science forces itself to run its own gauntlet*" (pp. 61). This is not a primary focus of this paper, and is therefore only mentioned briefly.

hygienic technology. Further, the potential risks associated with immunizations have the potential to transgress temporal and spatial boundaries. For instance, varicella vaccination may prevent a child from contracting chicken pox, but unlike immunity developed from exposure to the virus via disease outbreak, there is uncertainty about the duration of the vaccination-induced immunity. Could vaccination keep a generation of children from contracting chicken pox in elementary school, only to then increase the likelihood of a shingles epidemic when this generation reaches adulthood? On the other hand, however, not immunizing carries another set of risks. Decreases in herd immunity, for instance, combined with the ease of travel (especially likely for those people of means who are may also be able to 'purchase out' of some risks) spell the potential for global outbreaks of disease. In this hypothetical example, the perpetuation of global inequalities may be reinforced: a small segment of wealthier or more educated parents, who have 'spared' their children the risks of vaccination, may help transmit disease to others who may be under-immunized due to lack of availability. While there is little evidence that this has happened, the trend of vaccine rejection is still new and its implications may not have yet reached their height.¹¹ Within the same society, inequalities are also perpetuated; parents with the economic and social resources to change doctors or pay for alternative care may be able to enact their will to not vaccinate, whereas other parents may question or oppose vaccination but be unable to have their vaccine related decisions carried out.

Another way in which Beck's theory fits the phenomenon of vaccine refusal is the contested nature of expert knowledge. Assessments of vaccination-related risks happen in

¹¹As an illustrative example, a CDC advisory on July 31, 2004, however, reported a confirmed case of measles in an unvaccinated two year old child returning to the United States from travel in Hong Kong, Thailand, and China. The child was in the infectious stages of measles during the return flight to the US. Other American passengers on the flight reside in 16 different states, Washington, DC, and Puerto Rico. *CDC Health Advisory*, distributed via email: Health Alert Network, August 1, 2004.

an environment where parents are increasingly aware of the conflicting claims about side effects, vaccine efficacy, and safety. This is particularly highlighted with the increase in the number of vaccinations offered or required. Are newer vaccinations safe? What are the effects of combining multiple antigens into one shot? Parents may also be aware of and concerned about the non-neutrality of experts. Doctors conducting vaccination research may be on pharmaceutical company payrolls, for example. Or parents may be concerned about vaccine-related information coming to them from pharmaceutical companies through their physicians. These factors are likely to influence parental decision about immunization. As evidenced by trends in patients questioning medical recommendations generally and vaccines more specifically, it seems that parents are in the business of individual risk assessment and management for their children. The irony is that modern people try to be rational in their decision making, but the ever-expanding sources of information provide more uncertainty and more potential for risk to be defined. Popular press and scientific publications may report studies linking vaccines with risk, and the next day a conflicting study may be released. (This was the case with the MMR-autism controversy.) Medical developments have made the world more knowable and have provided more opportunities for health, longer life, and freedom from disease, but have also made the world less predictable and less controllable. All of these patterns are recognizable in parental resistance to immunizations.

This research project uses Beck's framework to examine how variations in parental perceptions about elements of risk society may relate to vaccine related concerns, and to map the process by which vaccine concerns may influence vaccine related behavior. This research assumes that contemporary America is a risk society, and that individual members of society vary in the degree to which they perceive the variety of risks that may exist. There are, of course, a multitude of different arenas in which people may perceive risks.

While Beck's original work focuses more on environmental risks, in the present work I limit my examination to health related risks. Specifically, I investigate health related risk awareness and health risk mastery: parents' perceptions of how risky the world is in general, and their beliefs about their ability to intervene or moderate the risks their families face. These are operationalizations of Beck's elements of risk assessment. I also include in my analysis an operationalization of Beck's notion of contested knowledge. As it applies to the current project, I examine parental attitudes and beliefs about their trust or skepticism about government, corporations, medicine and science. This work seeks to establish if and how parental attitudes and beliefs regarding health related risks and mistrust or skepticism of authority knowledge will inform vaccination beliefs and behaviors. In terms of lived experience, beliefs about risk or the knowledge of experts are not likely to be entirely antecedent to vaccination beliefs. It is most probable that there is reciprocal causation amongst elements of Beck's theory (perceptions of risk and mistrust), as well as from vaccination beliefs to parental attitudes about risk and their level of mistrust. For the purposes of analysis, however, I assume that risk management and expert knowledge mistrust are antecedent to vaccine beliefs and behaviors. This is explored further below.

CHAPTER 2

METHODS

This project aims to uncover the social processes involved in parental questioning of and resistance to vaccination. Consistent with Beck's theory of the risk society, I propose that variations in parental beliefs and perceptions of modern risks and skepticism or mistrust of expert knowledge systems will predict parental vaccine decision making. Further, I posit that social status and social support will moderate the relationship between parental attitudes and beliefs and their immunization decisions. The conceptual plan for my analysis shown in Figure 2.1 on the next page.

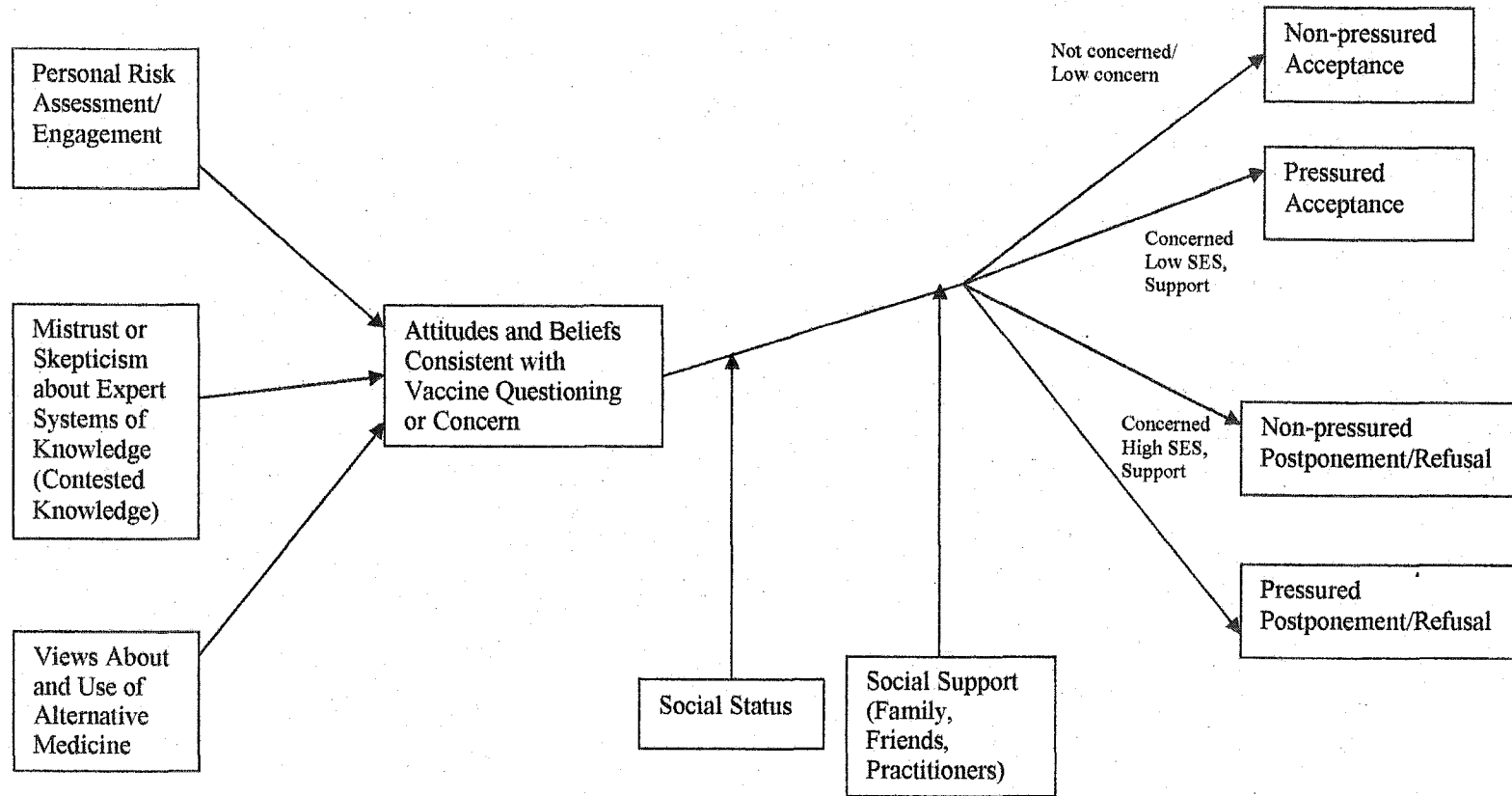


Figure 2.1 Conceptual Plan

Research Aims

Based on the literature review presented in the previous chapter and the conceptual framework (Figure 2.1), I have identified several specific research questions guiding the present study. These include:

- 1.) What is the prevalence of vaccine-related concern in the population of parents with children aged 13 or under?
- 2.) How commonly do parents decide to postpone or forego immunization for their children?
- 3.) Are there pressured acceptors of vaccination, and if so, how common is this?
- 4.) What are the most popular sources of vaccine related information for parents who postpone or forego immunization? Are there differences between vaccinating versus postponing/foregoing parents in the sources of child health related information on which they rely?
- 5.) Do vaccinating and postponing/foregoing parents report a difference in their children's health status? In other words, are parents who postpone or forego vaccinations opting out because of pre-existing health issues their children have?
- 6.) What role is played by social support in parents' decisions about childhood immunizations?
- 7.) Are different parental characteristics and statuses related to different vaccine concerns?
- 8.) How are parents' perceptions of health related risks and their beliefs about their ability to mediate risks related to vaccination uptake?
- 9.) How does mistrust of government, corporations, medicine, science and pharmaceutical corporations influence vaccine uptake?
- 10.) Are wealthier and more highly educated people more likely to be active non-acceptors of vaccination?

- 11.) Are parents who hold beliefs in keeping with an alternative lifestyle — including seeking medical care from chiropractors, homeopaths, or naturopaths — more likely to forego or postpone vaccinating their children?
- 12.) Are socially marginalized parents (minorities, those with lower incomes, and people with public insurance) more likely to be passive acceptors of vaccination? Will marginalized parents express more difficulty getting their vaccine-related questions answered? Will they feel more pressure from physicians and schools/daycare providers to vaccinate? What is the influence, if any, of marginalized status on parental vaccine acceptance?
- 13.) Are there direct effects of health risk mastery and awareness, mistrust of expert systems of knowledge, and alternative medical orientations on vaccination behaviors (as posited by the conceptual model), independent of one another and demographic factors?
- 14.) Is the relationship between elements of risk society and vaccination behavior mediated by vaccination concerns?
- 15.) Is there evidence to support a conditional relationship between vaccine concern and behaviors (with or without the context of pressure), moderated by the influences of social status and/or support variables?

To fully explore these research questions, both qualitative and quantitative data have been gathered. Since this research seeks to examine the emerging trend of parental questioning of and refusal of vaccination, qualitative methods provided me with a place to begin examining this new phenomenon. Qualitative interviews generated data about how non-vaccinating parents arrived at their decisions to not vaccinate. These interviews also queried parents' specific concerns about vaccinations (long term side effects, necessity of immunization, etc.), their experiences with health care providers once they had decided not to vaccinate, and how they navigated school vaccination mandates. A wealth of other data

was generated, including the emergence of vaccine questioning as a social movement and parents' engagement with social activism around vaccine issues. These data will not be reported in the present work. The main function of the qualitative data, for the purposes of this dissertation, was to inform the development of the survey instrument. Beginning with experiences of non-vaccinating parents allowed me to identify the beliefs, attitudes, and social experiences that shaped their decisions.

Since a larger part of this project is to explore the emergence of the trend in the general population, a population based survey was conducted. Ideas for the survey questions germinated from qualitative interviews. The survey probes the concerns of non-vaccinating parents (as were expressed in the qualitative interviews) in both vaccinating and non-vaccinating parents. The survey generated data allowing me to begin to examine differences between vaccine acceptors and rejectors/questioners. At the outset it is critical to note that the relatively small number of completed surveys will restrict many population inferences. It is my plan, however, that the quantitative data reported here will serve as pilot data for a larger study on this issue.

Part One: In Depth Qualitative Interviews

Sample

Interview respondents were parents who had made the decision to postpone or forego vaccination for their children. Interviewees were either direct contacts of mine, or they were based on referrals from other interviewees ("snowball sampling"). Initial respondents were personal contacts in Rhode Island, Massachusetts, and New Hampshire. This group of personal contacts will be referred to as Cluster 1. Interviewing began in July 2002.¹² At the same time initial personal contacts were being interviewed, I posted a

¹² Interviews were supported in part by a summer research fellowship through the University of New Hampshire Graduate School.

general message describing the research and soliciting interview participants to the automatic email list server (listserv) of a sociology-related professional association. From this posting, other contacts were made. This group of contacts will be referred to as Cluster 2. The posted listserv message asked recipients to forward the message along to others who may be interested. All the interview subjects reached via the listserv posting will be counted as part of Cluster 2, even though there were sub-groups of respondents who were the "second generation" of Cluster 2: respondents who were referred by people from Cluster 2 via the passing along of my message. Communication with Cluster 2 subjects was initially done via email then telephone.

The recruitment of interview subjects for a sociological research project from a sociology-related listserv may, at first glance, seem inappropriate. To address this concern, I only interviewed two mothers who responded from the sociology group. Their interviews were strikingly different from one another. Further, each of these two interviews showed more similarities with other non-sociologist parents than they did with each other. Another concern may be that a general posting to an electronic list may be a problematic way of recruiting subjects, as the electronic message may have been forwarded to any number of other readers and potential subjects eventually would not be able to be traced to the source from which they became aware of the project. This, however, did not seem to be a problem as I was trying to contact interview subjects through as many avenues as possible. Since the qualitative work was largely exploratory, I was eager to make contacts as disparately as possible and electronic posting achieved this.

Cluster 3 was established in November 2002 after I attended the national conference in Arlington, Virginia of a vaccine-information group. Over 500 participants were in attendance. During a question and answer session, I addressed the group and briefly stated that I was a graduate student at the University of New Hampshire and I was researching how parents had made the decision to not vaccinate their children. I said I was

interested in speaking with parents who might be interested in being interviewed after the conference. I subsequently made contact with over 50 parents; some parents preferred to take my contact information and establish contact themselves while others gave me their names, email addresses, or telephone numbers. During the remaining day and a half of the conference, I tried to talk to as many parents as I could. These informal conversations helped to shape the questions I asked in subsequent interviews. After the conference, I was able to talk with several of the parents from whom I had received contact information and some of those who had asked me for my information followed up with me.

One of the people to contact me was a speaker at the conference described above. Dr. Y, as I shall refer to him, is a chiropractor and administrator of a chiropractic college in the western US. While Dr. Y fit the interview criteria, his only child had congenital birth defects and a compromised immune system which, he recounted, were the primary influences on his vaccination decisions. Thus, I decided not to interview him. Dr. Y, however, was addressing a group of chiropractors in Manchester, NH in December 2002, and he invited me to attend the address. Further, he kindly gave me the opportunity to briefly speak to the assembly and extend the invitation to attendees who wanted to be interviewed. The group of subjects I met through Dr. Y is referred to as Cluster 4.

Initial interviews with Cluster 1 interviewees were conducted in a face-to-face setting, mutually agreed upon by the researcher and interviewer. Because of the nature of sampling, however, most interviews from other clusters were conducted by telephone. All interviews were taped after securing interviewee consent. No compensation was offered to respondents.

Design

Interviews ranged from forty-five to one hundred minutes long, and questions were asked in an open-ended format. Interviews were initially based on an interview guide that was informed from informal discussions with primary care physicians and parents who

expressed concerns about vaccinations, popular press coverage of potentially vaccine-related adverse reactions, and a review of the literature. Questions were added and modified as interviewing progressed. The final interview guide is shown in Appendix C. The order questions were asked differed from interview to interview, but all interviews opened with the researcher briefly describing the research project and reviewing informed consent guidelines (Appendices A and B). In-person interview subjects signed consent documents and received a copy for their records. During telephone interviews, I secured informed consent once again after taping began to document verbal consent.

Respondents were then asked to, "Tell [me] your story. How did you come to your decisions about vaccinations?" Interviews generally proceeded as a narrative. While interviews were largely unstructured, there were several content areas that were queried or probed, based on whether the respondents broached the topics or whether I raised the subjects. These topics included: sources of vaccine-related information; familiarity with popular press coverage of vaccine controversies; experiences with suspected vaccine adverse reactions in themselves, their children, or other family members; reactions to their decisions from significant others including spouses and/or co-parents; experiences with doctors; concerns about other medical recommendations and interventions; attitudes about state imposed mandates; and parents' styles and philosophies such as attachment parenting, breastfeeding, diet, and homeschooling.

It was anticipated that most interviews would be with mothers, as mothers are more likely to be primarily responsible for the health care decisions of their children. In cases where both parents were involved in immunization decisions, attempts were made to interview both parents. Seven subjects were male, twenty-eight were female. In total, 35 interviews were completed. Ten interview subjects were recruited from Cluster 1; ten from Cluster 2; twelve from Cluster 3; and three from Cluster 4. Interview subjects came from fifteen states. Numbers in parentheses indicate the number of interviews: CA(1), CO(1),

FL(1), IL(2), KS(1), MA(3), MD(4), NC(1), NH(5), NY(5), OH(1), RI(5), TX(1), VA(1), WA(3). Eleven interviews were completed in person and the remaining twenty-four were conducted via telephone. Interviewing took place from July 2002 to April 2003.

Interview tapes were transcribed into text documents which were then coded using QSR NVivo qualitative data analysis software. Interviews were coded for major recurrent themes within the broad categories mentioned above. Emergent themes were also recognized and coded. For instance, analysis of themes revealed that in discussing state mandated vaccinations, several respondents mentioned mistrust of the government. This became a new theme, one that also crossed categories into concerns about medical recommendations, as other respondents discussed links between pharmaceutical companies, doctors, and the government.

Quotes indicative of themes were extracted, and frequently mentioned concepts were used to construct specific indicators. These indicators were then crafted into survey items. Thus, survey items were largely generated from non-vaccinating parents' own words and experiences.

Part Two: Telephone Survey

Sample

The survey population was all English language proficient parents of children thirteen years old and under with a residential telephone in the United States. The final recommended childhood vaccine, a tetanus and diphtheria booster, is generally administered between the ages of 11 and 12. Parents of children up to age thirteen, therefore, are likely to still have recollection of their experiences with making vaccination decisions. The sampling technique used was random digit dialing (RDD). Persons answering the phone were screened to determine whether there are children aged 13 and under in the household, if they are the parents or guardians of the children, and if they are

involved in the health care decisions for the children. For this study it was not necessary to select either mothers or fathers of children, as long as the respondent indicated involvement in their children's health care decisions.

The relatively small sample size is perhaps the largest limitation of this portion of the study, restricting the number of vaccine refusers and postponers available for analysis. Of the 310 respondents answering the question "Have you ever made the decision to postpone or not allow any vaccinations for any of your children," 20.97% (65) responded affirmatively. While statistical power limitations may reduce my ability to test larger multivariate models, the completed sample size is likely sufficient to address most research questions.

Nearly 77% of survey respondents were female (76.59). Respondents had an average of 1.76 children under age 13 in their homes, and the average age of children was 7.69 years old. The sample has English as the predominant language spoken at home (95.22%). Less than 12% had received Temporary Aid to Needy Families (TANF) within the last year, while nearly 21% of respondents claimed that they had a child who was ensured by public insurance within the last year. The majority of respondents (77.05%) stated that there were two adults in the household, and 82.19% responded that there was another adult whose income contributed to the household. Most respondents were employed (19.66% part time and 54.83% full time). The sample was also well educated; 73.88% of respondents had at least some college education (26.8% completed some college, 35.4% were college graduates, and 11.68% had completed post graduate work). Over 80% of the sample was white (80.62%), 8.3% black, 3.11% Asian, .69% Native American, 2.42% multiracial, and 4.84% of another race. Fifty-five percent of the respondents claimed an income of \$59,999 or less per year.

Design

This portion of the research employed a cross-sectional design of telephone surveys. A draft survey was developed and was revised based on data from interviews and ongoing review of the literature. Survey pretesting and pilot testing was conducted. Pretesting included cognitive interviews with ten parents, and a pilot study with a convenience sample of approximately 50 respondents was conducted. These two types of pretesting had two goals intended to reduce measurement error. First, survey questions were refined, extraneous and unnecessary items were identified and removed, and new items were added. Second, cognitive interviews assisted the researcher in identifying and correcting any misleading phrasing or unclear skip patterns.

Telephone surveying took place from February 28 through May 8, 2004. The telephone survey method was selected because of the advantages associated with this design. A main consideration was the time-to-cost convenience telephone surveying offers. Second, telephone surveys can be completed in a relatively short period of time, while providing the researchers with a high level of quality control over data collection. Third, the resources available to the researchers through the University of New Hampshire Survey Center strongly recommended this design. I actively monitored data collection, assisted with the training of telephone interviewers, and was physically present during the first half of data collection. The UNH Survey Center features a 24-station CATI system using WinCat by Sawtooth Software. This advanced computer system and supporting software help make the Survey Center one of the most advanced survey research organizations in New England.

The Survey Center has professional procedures in place to ensure quality control for data and extensive training for Survey Center interviewers. All interviewers attended intensive training sessions on survey research techniques before working on any projects. Interviewer training focuses on general social science research techniques and the use of

the CATI system. In addition, interviewers were given project-specific training for this survey by the principle investigator. The Survey Center is also equipped with telephone and screen monitoring systems which allow supervisors to listen in and unobtrusively monitor the conversations between interviewers and respondents as well as monitor what is displayed on the interviewer's computer screen. All interviewers were continuously monitored during the duration of the survey by the principle investigator and/or an experienced supervisor. This ensured that all necessary procedures were followed correctly and consistently.

A comprehensive strategy was employed to maximize the response rate. Repeated telephone calls to each selected respondent were made at varying times of different days. Due to budgetary restraints, most calls were made during the hours of 4 PM and 12 AM, EST. Selected telephone numbers were not replaced until each one was called twelve times. The Survey Center also has a toll-free number to provide an opportunity for respondents to contact the researcher at their convenience. All respondents who initially refuse to participate were contacted again by a more experienced interviewer after two days so that refusal conversion efforts could be initiated.

I calculated both response rates and participation rates. The response rate is the number of completed interviews divided by the number of interviews plus refusals plus non-contacted numbers multiplied by an estimate of the proportion of cases of unknown eligibility would be actually eligible. I employed the following formula:

$$I + P / I + P + R + [NC (e)]$$

where I is the number of completed interviews, P is partially completed interviews, R is refusals, NC is non-contacted numbers, and e is the estimate of eligibility. (This estimate was determined by applying the percentage of known eligible respondents among all screened households.) Using this calculation, the response rate was 19.60%. The

participation rate was 28.5%, based on a formula where the number of partial and complete interviews was divided by the sum of completes, partials, and known eligible refusals. The response rate is conservative since the estimate of eligibility was applied to all refusals even when refusing households were not screened, as a significant percentage of numbers called were not.

Telephone surveys have potential coverage error since not all people have telephones, and the likelihood of having a phone decreases for lower SES households. Given that only 2.4% of the US population has no telephone service (US Census 2000), however, this is not expected to bias my estimates. Another practical consideration potentially limiting my response rate is the increase in technologies allowing active call monitoring and blocking of unidentified numbers. The low response rate from this survey is in part a function of not being able to contact people. These may be people who are less likely to be home and are more socially active, relying on answering devices to capture their calls. These may also be people who are more suspicious of incoming calls, using call intercepting, answering, and blocking devices to screen out calls. While I do not know anything about this group of people, there is no particular reason to suspect that there is systematic bias in their non-response.

Measures: Dependent Variables

A summary table of all variables is presented in Appendix D. The survey instrument can be found in Appendix E.

Immunization status The survey contained questions related to each of the respondents' children's immunization history (q12a-q12g). Respondents were asked, for each child, if the child had received all, most, some, or none of the recommended vaccinations for his/her age.

Vaccine reactions Respondents were asked if they believe any of their children had ever had a bad reaction from a vaccine (q13). Less than 10% believed this to be the case, and these respondents were asked to state which vaccinations they suspected caused the reactions and to describe what the reaction was (q13a-q13a9). A separate item (q13b) asked if the reaction influenced their decision to give further vaccinations. Of the respondents claiming that they had a child who had suffered an adverse vaccine reaction, 40.74% stated that their future vaccine decisions had been influenced.

Vaccine questioning One item asked “have you ever had questions or concerns about the vaccines your child’s health care provider has recommended?” Thirty-one percent (31%) responded affirmatively. Of these parents, 17% felt their questions and concerns were not addressed by their doctors; this specific item asked “Do you feel the doctor answered these questions and addressed your concerns?”

Vaccine refusal One item (q16) asked “Have you ever made the decision to postpone or not allow any vaccination for any of your children?” This dichotomous variable split the sample into two groups: those who had *ever* refused or postponed any vaccination versus those who *never* refused or postponed. Nearly 21% of respondents had postponed or refused a vaccination for a child. The group of parents who made the decision to postpone or forego a vaccination for any child are referred to in the remainder of this work as “ever refusers.” This is contrasted with “never refusers” who had not ever postponed or refused.

“Ever refused” respondents were asked to indicate which vaccines they had postponed or not allowed (q16_1 to q16_9). The list of vaccinations included: DPT, DTaP, or diphtheria, pertussis, and tetanus; polio; chicken pox or varicella; MMR or measles, mumps, and rubella; hepatitis B; HIB or haemophilus influenza; pneumococcal conjugate or pneumonia; flu; or another vaccine. Respondents were then asked their reasons for

postponing or not allowing each shot, and whether they are planning to give each shot eventually or would rather that their child never receive it.

Perception of pressure to vaccinate In addition to the dichotomy of “ever” and “never” postponing/refusing, a more nuanced distinction was made between those parents who perceived pressure to vaccinate their children. Thus, within each of the vaccination uptake groups (“ever” and “never”), respondents were sorted by whether they felt pressure or not. The resulting variable is nominal with four categories: ever postponed or refused a vaccination and felt no pressure to vaccinate (13.87%); ever postponed or refused but perceived pressure to vaccinate (7.10%); never postponed or refused a vaccination and felt no pressure (69.68%); and never postponed or refused, but experienced pressure to vaccinate (9.35%). Table 2.1 below displays this typology.

TABLE 2.1 Typology of Vaccination Decisions and Pressure

Vaccine refusal or postponement?	Vaccination Acceptance?	Experienced Pressure to vaccinate?
	Ever postponed or refused (N=65, 20.97%)	
Ever postpone/refused, felt pressure (N=22, 7.10%)		
Never postponed or refused? (N=245, 79.03%)		Never postponed/refused, felt no pressure (N=216, 69.68%)
		Never postponed/refused, felt pressure (N=29, 9.35%)

Measures: Independent variables

Sources of information Items q24-q35 query the sources of information from which parents get child health information. Sources included: television, magazines, books, Internet, medical journals, family or friends, doctors, nutritionists, chiropractors, acupuncturists, naturopaths, and herbalists. Response summaries are in Appendix D, Table D.1

Health-related risk awareness and engagement Eight items (q56rec, q57rec, q59rec, q67rec, q68rec, q69rec, q70rec, and q72rec) asked about respondents' beliefs and perceptions of risk. All belief items were measured on a Likert-type scale, with higher scores indicating greater agreement with the statement. Respondents were asked their level of agreement (strongly agree, agree somewhat, disagree somewhat, or strongly disagree), with the neutral response "neither agree nor disagree" only coded when respondents volunteered this. Negative items were reverse coded. Raw data were recoded to include the neutral responses. See Appendix D, Table D.1 for item summaries and Table D.2 for factor loadings of composite variables.

Using these eight items, two composite indices were constructed. Using Intercooled Stata 7 software, I explored the underlying dimensions of the risk construct by employing principle components factoring and principal factoring with iterated communalities. Both analytic techniques indicated the presence of two factors. Orthogonal and oblique rotation of items was conducted to calculate factor loadings. Items q56rec, q59rec, q67rec, q68rec, and q72rec loaded most strongly on one factor, while the remaining three risk items (q57rec, q69rec, and q70rec) loaded on the other. New variables were created with factor weights based on oblique rotation results, as the factors are likely to be correlated. The first new variable was called *riskaware*, indicating that items in this scale variable reflect respondents' awareness of health related risks. The second risk variable is comprised of items that appear indicating of respondents' health-related mastery, or sense that they can control the risks their children and families face; accordingly, this new variable was called *riskmastery*. Risk awareness items have a Cronbach's alpha reliability of .59 and risk mastery items have an alpha of .62.

Mistrust or skepticism about expert systems of knowledge Eleven items (q43rec, q54rec, q55rec, q73rec, q74rec, q75rec, q76rec, q77rec, q78rec, q79rec, and q80rec) queried respondents agreement with items related to mistrust or skepticism about medicine,

science, government, and corporations. As explained in the previous section, principal components factoring and principal factoring with iterated communalities were run on these items, with both techniques yielding similar results. Two factors were scored. These reflect two dimensions of skepticism: questioning of science and medicine (called *mistrustsci*) and mistrust of government and corporations (called *mistrustgovt*). These scales have Cronbach's alphas of .51 and .75, respectively.

Attitudes and beliefs about immunization Eleven items (q44rec, q45rec, q46rec, q47rec, q48rec, q49rec, q50rec, q51rec, q53rec, q58rec, and q60) included in the survey were intended to assess respondents' beliefs about immunizations. Similar items were found in Gellin et al (2000). As with other attitudinal measures included in the survey, responses were on a Likert scale with higher scores indicating greater agreement. Items were recoded to include the respondent-volunteered neutral category, and were reverse coded where appropriate.

Factor analyses suggested the presence of two underlying dimensions. The first, called *vaxreg*, seemed to reflect attitudes and beliefs consistent with questioning of vaccine requirements, regulations, or policies (items q44rec, q45rec, q46rec, and q60rec), Cronbach's alpha, .71. The remaining items were scaled into a new factor weighted index, *vaxsafety*, related to vaccine safety concerns. Vaccination safety items have a Cronbach's alpha of .76.

Alternative medical orientation Two questions (q65rec and q66rec) asked about respondents beliefs about alternative medicine. These items were combined in a composite variable, *altmedview*, with a reliability coefficient of .51. In addition, there was a series of questions (q71a-q71g) about the types of medical care respondents' children have received. If a respondent had taken any of their children to a chiropractor, acupuncturist, naturopath, or herbalist, they were coded as having utilized alternative medicine services in the new dichotomous variable *altmeduse* (0=no, 1=yes). Two additional respondents answered that

they had taken children for cranial sacral therapy and one had consulted a midwife about the child's health; these respondents were also coded as users of alternative medicine.

Variables *almeduse* and *altmedview* will be used to assess the claim that parents with an alternative medical orientation will be more likely to resist or question immunizations (Lee, Li, and Kemper 2000, Lee and Kemper 2000, Perrin and Kemper 2000, Pinker 2000, Gellin et al 2000).

Social support Social support is assessed via the construction of three items. First, practitioner support is measured in the new variable *supportdoc*. This is a composite index resulting from factor analytic techniques on responses to items q37rec-q42rec. These items have been adapted from Snyder and Ware (1975). In Snyder and Ware's original study, scale items reflected individual satisfaction and the individual's perception of other's satisfaction with their care. Items in this study include only items related to the individual's perception of care given by the child's health care provider. Items include statements such as "Sometimes my child's doctor makes me feel foolish" and "I am encouraged by the health care provider to bring my child for regularly scheduled check-ups." These questions have been included to assess whether there is an association between interactions with medical care providers and immunization beliefs. If parents feel dissatisfied with the care their child receives or uneasy with the provider, they may feel marginalized, and therefore feel less likely to voice and have their vaccination questions answered. I also postulate that feeling dissatisfied will be related to pressured acceptance of vaccinations despite having concerns; for instance, a parent who feels foolish is less likely to raise questions and dissent with the recommendations made by physicians. Furthermore, these questions provide a measurement of the context in which parents are making their decisions. This could be a proxy for how much trust in medicine parents have. Items comprising *supportdoc* have a reliability coefficient of .68.

The second support index deals with respondents' perceived support from their family and friends, assessed through survey items q63rec and q64rec. These two variables were scaled into the new variable *supportff*, Cronbach's alpha .66. Finally, respondents' vaccination decisions are likely to be influenced by their inclusion in a network of other parents for whom postponing or foregoing vaccinations is normative. A new dichotomous variable, *nonvaxnetwork*, measures whether respondents have family or friends who have postponed or foregone vaccinations for their children.

Child health Children's health status may influence parent's attitudes towards immunization and decisions about whether to immunize. For instance, a child with an autoimmune disease may have a medically recommended reason for delaying or foregoing immunization that would not fall under the scope of vaccine refusal covered by this study. Items q6rec-q11rec asked about the respondents' children's general health status. Example items were "My child seems to be less healthy than other children I know" and "My children's health and physical development are similar to other children I know." These items are on a Likert scale with higher scores indicating greater agreement. These items were not combined into a scale because of the low value of Cronbach's alpha (.32).

Demographic variables The final section of the survey asked demographic questions. These items examine socioeconomic status and include questions about the language the family speaks at home, number of people in the home, whether the respondent has a child who has received been on a public insurance plan within the last year, family receipt of TANF, respondent employment, education, and income. Race and ethnicity are also asked. These variables will be used to test the hypotheses that there are differences in vaccine uptake, resistance, and questioning by race and SES.

Analysis Plan

The aim of this project is descriptive as well as explanatory. Because of these different aims, my analyses proceeded in several steps. First, I describe the characteristics, attitudes, and beliefs of vaccinating and vaccine postponing or refusing parents. These descriptive and largely bivariate analyses are presented in Chapter 3. It is in this chapter that I seek to answer research questions 1-12 presented at the beginning of the present chapter.

In Chapter 4 I present analyses directed at the conceptual model depicted in Figure 2.1. (Research questions 13-15 address this.) The complexity of the model requires several steps in the analysis, which proceeded in three stages. First, the possible independent effects of health risk awareness and health related mastery (two components of personal risk assessment and engagement), parental skepticism of systems of expert knowledge (science and medicine, and government and corporations), and alternative medical orientation (both in belief and use of alternative medicine) on vaccine uptake are assessed.

In the second stage of analysis, I explore the extent to which risk awareness, risk mastery, mistrust/skepticism, and alternative medical orientation have indirect effects on uptake, operating through vaccination concerns. It is important to note that while the conceptual model posits that risk beliefs, attitudes of skepticism about expert knowledge, and medical orientation are precursors to vaccination concerns, this is presented for the sake of conceptual clarity and simplicity. There is likely to be reciprocal causation at work in people's beliefs. Some parents, for instance, may arrive at their questioning of traditional medicine and scientific paradigms first, then later seek out alternative medicine. Others may have become skeptical of vaccinations, and then begun to question scientific knowledge or government intervention into public health. It is impossible to determine from these cross-sectional data where the attitudes and beliefs are generated and what the antecedent factors are.

Finally, the third stage of analysis considers whether the relationship between vaccination concerns and behaviors is moderated by social status and/or social support. Throughout these multivariate analyses (Chapter 4), I employ the four category variable, (displayed in Table 2.1) that combines vaccination decision with the perception of pressure.

CHAPTER 3

DESCRIPTIVE RESULTS

Overview

One aim of this research is to describe the characteristics of parents who question vaccinations, and those who postpone or forego immunizations. As mentioned in the previous chapter, it is possible that there are significant, meaningful differences between parents who vaccinate on a schedule that differs from what is recommended (postponers) and parents who choose to never allow a vaccination for a child (refusers). Also, there may be vaccination-specific differences between postponers and refusers, such that a parent could be a refuser of one vaccination while also postponing another. These more detailed threads of inquiry are interesting, and potentially important. Analysis along these lines, however, is not possible given the limited size of this sample. Throughout the results reported below postponers and refusers are collapsed into one group. Thus, a core distinction is made between those parents who have accepted vaccination (*never* postponing or refusing) and those who have *ever* postponed or refused any immunization for their children. When reporting results, I employ the shorthand *postponing/refusing* to remind readers that respondents in this category may have either delayed or foregone a vaccination.

I have speculated that there may be a finer grained distinction to be made between *ever* and *never* postponing/refusing parents in their experience of pressure on their vaccine-related decisions. I remind readers that I examine both *ever* and *never* postponing/refusing respondents in their experience of pressure from doctors, schools, and daycare providers. This combination of decision (*ever* or *never* postponing/refusing) and pressure (*yes* or *no*)

results in four categories which I refer to below as *decision-pressure* groups. In the following analyses, therefore, I identify significant differences in vaccine uptake groups (ever versus never refusing or postponing) to specify factors influencing *behaviors* around vaccination. In addition, I examine more detailed differences that also incorporate the experience of pressure to vaccinate. These latter analyses allow me to determine how external pressures and vaccine behaviors coincide to affect or reflect variations in attitudes, beliefs, or status characteristics.

Another caveat about these data is important to highlight. The small sample size has meant that some of the relationships uncovered in the following results are not as robust as they might be with more cases. While I would like to comply with convention and only report results that are significant at an alpha level less than or equal to .05, I have decided to also discuss marginally significant relationships ($.10 > p > .05$). This decision was informed by the goal of describing the phenomenon of vaccine questioning and resistance while working within the limitations of the data. Ignoring marginally significant associations would obscure relationships that might indeed be noteworthy. Future work with a larger sample, however, would proceed with a lower alpha level.

The results presented in this chapter are largely descriptive, reporting bivariate associations among core constructs and identifying variations across groups of parents. This chapter is organized to answer research questions 1-12 posed in the previous chapter. Following this I provide a chapter that aims to test the conceptual model presented in Figure 2.1. This model attempts to explain and predict vaccine postponement/refusal and vaccine decisions made under pressure.

Prevalence of Vaccine Concern

While all available evidence suggests that most parents want their children to be fully immunized, there is a growing trend toward parental questioning and possible refusal

of some vaccinations. Data from the present study reveal that 31.07% of parents had concerns or questions about the vaccinations their child's health care provider recommended. This finding is consistent with research Freed et al (2004) and the Centers for Disease Control (2002). In the present study, most respondents who had questions about vaccines were able to get their questions answered by their doctors (83.33% felt the doctor addressed their concerns). As would be expected if concerns translate into action, there is a relationship between concerns about vaccination and vaccine uptake behaviors: nearly 39% of parents with vaccination concerns also made the decision to postpone or forego a vaccination for their children, compared with only 13% of parents without vaccination questions, $\chi^2(1)=25.69, p<.001$. Furthermore, 63% of parents with unanswered vaccine-related questions postponed a vaccination for a child, versus 34% of those who felt their questions were answered, $\chi^2(1)=4.65, p<.05$. Clearly, decisions about whether or not to vaccinate are influenced by parents' level of concern about immunizations; when unable to resolve doubts, parents may not immunize according to the recommended schedule, or they may forego vaccination entirely.

Postponement/Refusal and Type of Vaccination

Twenty-one percent of respondents in this sample had made the decision to delay or refuse a vaccination. Of the 65 respondents postponing or foregoing a vaccination for a child, only 13 were vaccine refusers and the remaining 42 are postponers. Respondents who answered that they had postponed or foregone a vaccination are considered refusers if they responded, to any of the specific vaccination questions, that they would rather their child never receive that vaccination. Postponers responded that they would eventually allow the vaccinations or were undecided at the time. These categorizations, of course, are not mutually exclusive, as some parents will postpone one vaccination and not allow another.

The most commonly postponed or refused vaccination was varicella (chicken pox), with 31% of postponer/refusers delaying this vaccination; 60% responded they would eventually administer it. The most commonly cited reasons for postponing it were the newness of the vaccine and suspicion about the need for the vaccine; half of the parents postponing varicella vaccination cited these reasons. The second most commonly postponed immunization was pertussis-containing vaccination; 17% of postponers/refusers delayed it with 80 % planning to eventually allow it. Here safety and long term consequences were the greatest concerns for more than half the postponers. Both MMR and HepB vaccinations were named by 14% of postponing/refusing respondents, with the majority eventually planning to give the vaccinations (62.5% and 67%, respectively). Three of the eight parents postponing/not allowing MMR were concerned with safety or side effect issues. Concern about HepB vaccine was split between three issues: perception of disease contraction risk, lack of information about the new vaccine, or newborn inoculation. Eight percent of postponer/refusers withheld flu vaccinations, and nearly all would not ever allow it (40%) or were undecided (40%). Only 5% of postponer/refusers acted against the polio and Hib vaccines each, yet while 67% would administer polio, the same percentage would never allow Hib vaccination. Finally, 3% of postponer/refusers did not allow pneumococcal vaccination, and half would administer it eventually.

Pressured Acceptance

Are there pressured acceptors of vaccination, and if so, how common is this?

Pressured acceptance is defined as parental consent for a vaccination despite unanswered questions, unaddressed concerns, or the desire to not vaccinate. The present study, in seeking to describe the phenomenon of vaccine questioning, is interested not only in parents who decide to delay or refuse vaccinations, but also those respondents who may have vaccinated under pressure from doctors, daycare centers, or schools. These parents

are important because they may not feel that they have given fully informed consent. These parents may also form the next group of parents to become postponer/refusers, particularly as they make medical decisions for subsequent children. To the extent that these parents have characteristics that are different from non-pressured parents, they may be revealing about medical decision making and the social context in which decisions are made. In the present survey 16.45% of respondents (N=51) expressed that they felt pressure to vaccinate. Of these fifty-one, twenty-nine never postponed or refused a vaccination, but felt pressure to vaccinate from doctors, schools, or daycare providers. The remaining twenty-two of the fifty-one pressured respondents did postpone or refuse a vaccination. The two categories of pressured respondents may differ from one another in important ways. For instance, never postponing/refusing parents who felt pressure may also have persistent concerns about vaccinations, but may have social status characteristics that make it more difficult for them to enact their decisions to make alternative vaccination decisions. In the analyses elaborated below and in the next chapter, the characteristics of these four groups (accepting with no pressure; accepting with pressure; postponing/refusing with no pressure; and postponing/refusing with pressure) are examined more closely.

Sources of Vaccine Information

In order to better describe differences between vaccinating and non-vaccinating parents, I considered whether there were any variations in the sources of information on which they rely for child health information. A series of chi-square analyses were conducted to determine if there is a relationship between postponing/refusing a vaccination and twelve different types of information sources. Of these twelve areas of health information, there were significant differences between postponing/refusing and vaccinating parents in their use of magazines, chiropractors, and herbalists ($p < .05$), while differences in books and naturopaths as sources of information approached significance

($p < .10$). In each case, a greater percentage of the postponing/refusing group sought medical information from each of these sources. The percentages are reported Table 3.1 below:

TABLE 3.1 Percentages Relying on Various Sources of Health Information

Gets health information from:	Decision to postpone or forego vaccination for any child		χ^2
	No	Yes	
Television	43%	44%	0.05
Magazines	72%	85%	4.30*
Books	75%	85%	2.78†
Internet	58%	62%	0.26
Medical journals	37%	40%	0.19
Family and friends	71%	78%	1.37
Doctors	96%	98%	0.96
Nutritionist	23%	29%	1.02
Chiropractor	7%	15%	5.09*
Acupuncturist	83%	0%	0.54
Naturopath	3%	8%	3.17†
Herbalist	5%	12%	3.83*

† $p < .10$, * $p < .05$

That there is a significant relationship between immunization decisions and sources of health information such as chiropractors, naturopaths, and herbalists is consistent with the findings of Lee and Kemper (2000), who found that alternative medical practitioners are less likely to recommend vaccination. Of course, we cannot draw a conclusion about the direction of influence between immunization decisions and sources in health information: parents may make alternative vaccination decisions in conjunction with, prior to, or after seeking medical advice from various practitioners. That a greater percentage of ever postponing/refusing parents than never postponing/refusing seek health information from books and magazines is also interesting. Perhaps these parents are questioning the medical advice they receive from traditional sources, such as medical doctors, and are searching other forms of literature for information. This relationship requires further exploration.

To investigate if there are significant differences between groups of parents experiencing pressure on their vaccine-related decisions in the sources of information they rely on, chi-square analyses were conducted. Table 3.2 below displays the results.

TABLE 3.2 Cross Tabulation of Decision-Pressure and Sources of Information

Gets child health information from:	Ever refused or postponed, felt no pressure	Ever refused or postponed, felt pressure	Never refused or postponed, felt no pressure	Never refused or postponed, felt pressure	χ^2
Television	53%	27%	43%	45%	4.17
Magazines	81%	90%	72%	69%	5.16
Books	81%	91%	74%	79%	3.78
Internet	56%	73%	56%	76%	6.30 [†]
Medical journals	35%	50%	36%	48%	3.38
Family and friends	79%	77%	71%	76%	1.75
Doctors	100%	95%	96%	97%	1.87
Nutritionist	30%	27%	23%	28%	1.45
Chiropractor	12%	23%	7%	7%	7.40 [†]
Acupuncturist	0%	0%	1%	0%	0.89
Naturopath	5%	14%	3%	3%	6.63 [†]
Herbalist	5%	27%	5%	7%	15.63 ^{**}

[†] $p < .10$, * $p < .05$, ** $p < .001$

When the relationships between decision-pressure groups and health information sources are examined, only information from an herbalist is significant at a p-value less than .05. There are, however, relationships approaching significance between pressured acceptance and information from chiropractors ($p = .06$), naturopaths ($p = .085$), and the Internet ($p = .09$). In the case of herbalists, chiropractors, and naturopaths, a greater percentage of ever refusing/postponing respondents who also felt pressure to vaccinate sought health information from these sources. This may be because parents who have felt pressure to vaccinate yet still made alternative vaccination decisions relied on alternative and complimentary practitioners to support their decisions. In contrast, non-pressured parents who make alternative vaccination decisions may not feel the need to seek out practitioners who will support their decisions because they may already have support from

their child's health care providers (either traditional or complimentary). Pressured respondents, both vaccine acceptors and postponer/forgoers relied on the internet as a source of child health information more than non-pressured respondents.

Child Health Status and Vaccine Acceptance

Do vaccinating and postponing/foregoing parents report a difference in their children's health status? In other words, could it be that parents who postpone or forego vaccinations are opting out because of pre-existing health issues their children have? A series of t-test sought to determine if there were significant differences in the reported health status of respondents' children. The six health status items were not scaled because of the low value of Cronbach's alpha (.32). There were no significant differences in any of these health status items by whether the parents had decided to postpone or forego immunizations. Thus, vaccination behaviors are not seemingly related to child health status.

Yet, there are significant differences in child health amongst the four groups of decision pressure. One-way ANOVA results indicate significant differences between the four categories of ever/never postponing or refusing and pressure experience in agreement with the statement "I have a child who was once so sick I thought he or she may die," $F(3, 304)=2.91, p<.05$. Probes of pairs of means by Bonferroni's post hoc test revealed a significant difference between the means of never refused/postponed respondents who experienced pressure ($M=2.03, SD=1.30$) and those who did not ($M=1.47, SD=.98, p<.05$). Never refusing/postponing parents who reported experiencing pressure were in greater agreement with the statement that they had a child who was once so sick they thought the child might die than were never refusing/postponing parents who did not experience pressure.

There were significant differences between these four decision-pressure groups levels of agreement with the statement "My child seems to be less healthy than other

children I know," $F(3, 304)=3.43, p<.05$. In this case, pressure appears to matter for those parents who have never refused or postponed a vaccination. Post hoc analysis shows two significant pair wise comparisons. First, pressured but never refusing/postponing parents report greater agreement ($M=1.62, SD=.90$) than do ever refusing parents who do not report pressure ($p<.05$). Second, pressured but never refusing/postponing parents report greater agreement than non-pressured never refusers/postponers ($M=1.23, SD=.60, p<.05$).

Pressured but never refusing parents appear to report that their children are less healthy.

Finally, there were significant mean differences between groups' agreement with the statement "My children's growth and development are similar to other children of their age," $F(3, 304)=3.71, p<.05$. Again, pressured acceptance ($M=3.13, SD=.95$) versus non-pressured acceptance ($M=3.57, SD=.78$) accounts for the significant mean difference between pairs ($p<.05$). Greater agreement is reported by non-pressured vaccine acceptors than pressured acceptors.

These ANOVA and post hoc tests demonstrate a pattern where pressured vaccine acceptors report generally weaker child health than other groups. While a reason why is not clear from these data, perhaps parents who feel that their decision to accept immunizations was pressured are more concerned about the effects of immunization on their children and therefore see more problems with their children's health and development. Another possibility is that the children of pressured acceptors may be less well, and perhaps these parents had wanted to make alternative vaccination decisions on the basis of the child's weakened health but were unable to in the face of pressure.

Social Support and Alternative Immunization Decisions

It is hypothesized that there will be significant social support differences between parents making different vaccination decisions. I speculate that parents making alternative vaccination decisions ("yes" on q16) will have significantly different levels of social

support than those who have not decided to postpone or forego immunization. I do not, however, postulate the direction of this relationship. This is because parents who choose to postpone vaccination may feel more empowered to make an alternative decision with the support of others behind them, or they may feel less support because they are making decisions that go against a traditional course of medical action. I also postulate that social support will differ for the pressured and non-pressured parents: specifically, parents who felt pressure to vaccinate will feel less social support, especially from doctors, than those who did not feel pressured. Social support is measured in three domains: support from family and friends (*supportff*), support from doctors (*supportdoc*), and membership in a social network where alternative vaccination decisions are normative (*nonvaxnetwork*).

Analysis reveals that while there is no significant difference between vaccinating and postponing/refusing parents in the support they perceive from doctors, a difference of means test shows that parents who postpone or forego vaccination had significantly less perceived social support ($M=-.17, SD=.92$) from family and friends than did respondents who immunized on schedule ($M=.05, SD=.78$), $t(293)=1.90, p<.10$. Similarly, 42% of parents making the decision to postpone or forego a vaccination for a child were in a network of others who had also postponed or foregone vaccinations. This is compared to 25% of parents who had not postponed or foregone immunizations who had family or friends who had, $\chi^2(1)=6.55, p<.01$.

When examining differences in vaccination behaviors in the context of pressure, results from a one-way ANOVA show significant mean differences in social support from family and friends by decision-pressure group, $F(3, 291)=2.62, p<.10$. Pair wise comparisons reveal significant differences between pressured refusing/postponing respondents ($M= -.403, SD=1.09$) and non-pressured never refusing/postponing respondents ($M=.072, SD=.773$), $p<.10$. As higher means indicate more support, non-pressured vaccine

acceptors feel significantly more support from family and friends than do pressured postponer/refusers.

Similarly, statistically significant differences in perceived social support from doctors appears between groups of decision-pressure, $F(3, 292)=7.91, p<.001$. Post hoc analysis shows four significant differences between pair means. Consistent with the hypothesis that pressured respondents will report lower perceived social support, non-pressured ever refusing/postponing respondents ($M=.229, SD=.497$) report greater social support from doctors than pressured ever refusing/postponing respondents ($M= -.651, SD=1.51$), $p<.001$. Non-pressured refuser/postponers even report significantly greater physician social support than pressured vaccine acceptors ($M= -.392, SD=.820$), $p<.05$. Pressured refuser/postponers report less support from doctors than non-pressured acceptors ($.071, SD=.789$), $p<.001$. Finally, pressured acceptors report less physician social support than non-pressured acceptors, $p<.05$. Clearly, pressure to vaccinate is related to perceiving less social support from doctors. It is interesting to note that there is no significant pair wise mean difference between pressured refusers/postponers and pressured acceptors of vaccination. This would suggest that regardless of the vaccination decision, the experience of pressure is key to understanding the perception of social support.

Finally, there is a significant relationship between decision-pressure group and being in a network of family and friends in which alternative vaccination decisions are made, $\chi^2(3)=17.00, p<.001$. Fifty-nine percent of pressured refuser/postponers are in a network of others who have not vaccinated, followed by 46% of pressured vaccine acceptors. This is compared to 33% of non-pressured refuser/postponers and 23% of non-pressured acceptors who have family and friends who have not vaccinated.

These findings indicate that support for alternative decisions is an important factor in questioning conventional medical practices, withstanding pressure to vaccinate, and

enacting one's decisions to take a path different from what is normative in the medical culture.

The Role of Education and Income in Vaccine Concerns and Uptake

It is hypothesized that parents who differ in their concerns about vaccination are likely to make differing vaccination decisions. Before investigating whether vaccine concerns influence vaccine uptake, a relationship I examine in the next chapter, I first investigated if any significant relationships exist between parental social status characteristics and concerns about vaccination. I first investigate whether there are differences in vaccine questioning by education and income. (Vaccine questioning is measured by the dichotomous items asking "Have you ever had questions or concerns about the vaccinations your child's health care provider has recommended?") Next, I look at the two vaccination concern variables tapping two dimensions of concern: vaccine safety (the composite variable *vaxsafety*) and policies requiring vaccination (the composite variable *vaxreg*).

Pescosolido et al (2001) report that education decreases confidence in physicians. While confidence in doctors is not the same concept as questioning specific medical recommendations, I hypothesized that higher SES parents would express more vaccine related questioning. There may be several reasons for this. Higher SES parents, for instance, would presumably have more access to debates about vaccinations and may be more comfortable expressing their concerns with physicians. More highly educated parents may also hold beliefs consistent with alternative or new age philosophies (Streefland et al 1999) that may take issue with traditional medical knowledge.

Results indicate support for the hypothesis that education is related to vaccine questioning (here assessed with the item "Have you ever had questions or concerns about the vaccinations your child's health care provider has recommended?"). There is a

significant relationship between education and vaccine questioning: 39% of respondents who had graduated college had vaccine questions or concerns, versus 33% of respondents with some college, and only 18% of respondents with a high school level or lower education, $\chi^2(2)=9.85, p<.01$. Further supporting the hypothesis that higher SES parents will have more vaccine questions, there is a significant difference in income between those who had vaccine questions and those who did not. Vaccine-questioners reported higher mean income ($M=4.82, SD=1.68$) than those without questions ($M=4.05, SD=1.85$), $t(252)=-3.15, p<.01$.

I also hypothesize that education is related to specific concerns about vaccine safety and regulations. I do not, however, speculate about the direction. Parents with more education may have more exposure to scientific and medical research and therefore be less concerned about vaccine safety, believing that vaccines are safe. Alternately, parents with more education may have more exposure to the debates about vaccine safety, or may be more skeptical of scientific knowledge in general. There are also contending alternatives about the relationship between education and concerns about vaccine regulations. More highly educated parents may be less concerned about vaccine regulations because they support immunization and do not oppose mandates. On the other hand, more education may bring more of a critical eye toward government imposed mandates; in this case higher education would be associated with greater concern about vaccine regulations and policies.

A one-way analysis of variance showed that concerns about vaccine regulation increase with respondent's education, $F(2, 243)=2.41, p<.10$. (Since this finding is weak, perhaps due to the non-normally distributed distributions of vaccine regulation concerns across groups, a confirmatory Kruskal-Wallis test was conducted. Results of this test confirm the findings of marginal significance from the ANOVA: $\chi^2(3)=5.82, p=.054$.) Yet, while there are educational differences in regulation concerns, there were no significant income differences in concerns about vaccine regulations.

The second vaccine concern domain I tested was vaccine safety. As was the case with vaccine regulation concerns, there were significant vaccine safety concerns by education, $F(2, 243)=3.06, p<.05$. As education increased, vaccine safety concerns increased. There were no significant differences in vaccine safety concerns by income.

While group variations in vaccine concerns are important, I am also interested in parents' behaviors. To the extent that they may be more critical of science and medicine while at the same time being better situated to seek out other health care venues, higher income and education are likely to be related to actual vaccination uptake. To test this hypothesis, I examined income and education differences between vaccination acceptors and postponer/refusers. I hypothesized that alternative vaccine decision makers will have more education and income than those who never postponed or refused.

It appears that along with educational differences in vaccine questioning, there are educational differences in alternative immunization behaviors; there is a significant relationship between education and vaccine postponement/refusal. Respondents who had ever postponed or refused a vaccination reported having more formal education ($M=5.38, SD=1.28$) than those who never postponed or refused ($M=4.97, SD=1.48$), $t(289)= -2.05, p<.05$. There is no significant difference in income of those who postpone/refuse vaccination versus those who do not. These results provide support for the findings reported in the literature regarding the relationship between education and confidence in medical professionals (Pescosolido et al 2001) and education and skepticism about traditional medical knowledge (Streefland et al 1999). The current research also supports Gellin et al's (2000) finding that a greater percentage of people with a college education opted out of one vaccination than parents with a high school education.

I next sought to examine if there were education and income differences between decision-pressure groups. I had no specific hypotheses about these results. One-way

ANOVA results show no significant mean differences in income or education by decision-pressure groups.

The Role of Marginalized Statuses on Vaccine Questioning and Refusal

As we have seen, education is significantly related to both vaccine questioning and uptake. Respondents with more education are more likely to have vaccine concerns and to either postpone or forego vaccinations. But are other social statuses, particularly those that are marginalized, related to vaccination beliefs, concerns, and behaviors? There are four additional social status variables I investigate here: receipt of Temporary Aid to Need Families (TANF) or food stamps within the past year, children's coverage by public health insurance programs, English as the primary language spoken in the home, and minority status. Each of these variables is dichotomous.

I hypothesized that marginalized social status will be related to vaccine concerns; this broad contention, however, is largely speculative based on the dynamics of stratification in the United States. People with public insurance, for instance, may have more trouble accessing reliable, consistent health care, and may therefore have more questions or concerns about the recommendations made by the physicians they see. On the other hand, vaccine concerns may be lower among this group of parents, as they are struggling to get health care rather than questioning or refusing it. Thus, I consider two alternative hypotheses relating social status to vaccine concern.

In keeping with the literature (Gellin et al 2000), I expected that minority and non-minority parents would express significantly different levels of concern related to vaccine regulations and policies. This speculation finds root in Gellin et al's finding that a greater percentage of African American parents considered vaccination requirements as a principle motivation to immunize than white or Hispanic parents. If this relationship were to be supported in the present data, we might expect that minority parents would express fewer

concerns about vaccine regulations than non-minority parents since mandates may be motivating minority parents to vaccinate. On the other hand, if minority parents are vaccinating because of mandates, they may still be skeptical about being required to immunize; minority parents, therefore might express greater concern about vaccine regulations and policies.

A chi square analysis assessing differences in responses to the question "Have you ever had questions or concerns about the vaccinations your child's health care provider has recommended" by minority status was not significant. There was, however, a significant finding when specific vaccination concerns were examined. A difference of means test found that minority parents expressed significantly lower scores on the composite vaccine regulation concerns item ($M=-.205$, $SD=.663$) than did non-minority respondents ($M=.044$, $SD=.929$), $t(251)=1.71$, $p<.10$. While these data reported here do not allow me to test whether minority parents consider mandates as a motivation to immunize (as did Gellin et al 2000), this results shows that minority parents are not as skeptical of mandates as are non-minority parents. There were no minority status differences in vaccine safety concerns.

Further analyses showed that there were no significant differences in vaccine questioning by receipt of TANF, food stamps, or public insurance, nor whether English is the primary language spoken in the home. In examining specific vaccination concern domains, there were also no significant differences in vaccine regulation or policy concerns by language, TANF or food stamp receipt, or public insurance coverage; nor were there vaccine safety concern differences by minority group membership, TANF or food stamp receipt, or public insurance coverage. The only demographic variable significantly related to safety concerns was language spoken in the home, with English speakers expressing significantly less vaccine safety concern ($M=-.01$, $SD=.90$) than respondents who speak another language in the home ($M=.51$, $SD=1.11$), $t(246)=1.96$, $p<.05$.

Examining vaccination behaviors, there were no significant differences in ever or never postponing/refusing a vaccination by TANF/food stamp receipt, language spoken at home, or public insurance coverage. There is, however, a relationship between minority status and alternative vaccination decision making. Twenty-three percent of non-minority parents had postponed or refused vaccination, compared to only 12% of minority parents, $\chi^2(1)=3.41, p<.10$.

There were no significant relationships between the marginalized social status variables and respondents' decision-pressure group. This is consistent with the other findings. If lower SES parents are not generally questioning vaccines, this may indicate that they are accepting vaccination without experiencing pressure.

While language spoken in the home is related to vaccine safety concern, it is not related to vaccination behaviors. Further, the results relating to minority status correspond with one another; minority respondents report less vaccine regulation concerns and are less likely to postpone or forego vaccinations. These results, along with significant education difference in general vaccine questions, specific domains of concern, and uptake, begin to develop a picture in which vaccine skeptical parents are largely white and well educated. To be more specific, it is not low SES or marginalization that are associated with needling vaccine doubts, but rather the dynamics of privilege.

Perceptions of Health Risk and Health Related Mastery

Beck's theory of the risk society specifies that in a risk society (as is characteristic of modern culture), people as individual actors engage in personal risk assessment and that this influences their behaviors. Applying this argument to vaccination behaviors, I hypothesize that respondents with greater awareness of health-related risks will be different in their vaccine uptake. I also contend that respondents' perceptions of their ability to moderate the risks their families face will influence their vaccine decisions. The health

awareness variable I employ looks at general health related risks, not risks from vaccinations. Similarly, respondents' risk related mastery conceptualizes the respondents' ability to avoid general health risks. Vaccination uptake is measured as ever refusing or postponing a vaccination versus never postponing/refusing.

At the outset of the analyses I did not clearly posit a direction of the difference across groups, however, as there are again contending possibilities concerning the nature of the relationship. Respondents who have greater awareness of risks may be more ready to eschew vaccination, particularly if they are concerned about vaccine safety. In this way, they may be engaging in risk avoidance by refusing to immunize. On the other hand, a more heightened sensitivity to the presence of health risks may encourage parents to vaccinate their children in order to confer some of the benefits of inoculation. In this scenario, too, parents may be engaging in risk avoidance. Respondents who feel a greater ability to mediate the risks their families face may be more likely to postpone or forego vaccination (particularly if they also perceived vaccination risk). Or, accepting vaccination may be an expression of mastery, as vaccine uptake may be a way parents exercise their ability to mediate risks of disease contraction. Finally, it seems likely that there will be a significantly higher level of health related mastery expressed by respondents who do not feel pressured to vaccinate their children. Thus, I expected to find lower risk mastery among pressured acceptors of vaccination than in ever refusing/postponing respondents (regardless of pressure experience) or non-pressured acceptors.

To assess whether respondents' beliefs about health risks are related to vaccine uptake, I conducted a difference of means test. Contrary to what I hypothesized, there were no significant differences in health risk awareness by vaccination uptake categories (postponer/refusers vs. acceptors). I also ran a difference of means test to examine the relationship between vaccine uptake and risk mastery. As with risk awareness, there were

no significant differences between respondents who had ever refused/postponed a vaccination and those who had not.

Next, I investigated differences in risk perception and risk mastery amongst respondents who made different vaccine decisions and experience differential pressure. There is no difference in risk awareness by ever and never refuser/postponers, with or without pressure. There is, however, a significant difference in mean risk mastery by decision-pressure groups, $F(3, 272)=4.17, p<.01$. Post hoc analysis shows that the significant pair wise mean difference exists between never refuser/postponers who felt pressure and those who did not. Pressured acceptors have significant less risk mastery ($M=-.468, SD=1.11$) than do non-pressured acceptors ($M=.097, SD=.703$), $p<.01$.

The finding that general health risk awareness does not differ by vaccine uptake seems to be inconsistent with Beck's theory. This may suggest that the theory of risk society may not hold in the case of vaccination acceptance behaviors, or it may be that the general health risk variable is too non-specific to relate to specific behaviors. Thus, in the next chapter I examine whether risk awareness is related to vaccine beliefs, and if those beliefs are in turn related to vaccination behaviors. Before getting to this piece of the model, however, I examine risk dimensions as predictors of vaccine concerns in the next section presented below.

The finding that risk mastery is related to decision-pressure group is consistent with my hypothesis. Parents who accept vaccination and do not feel pressure are logically going to report high levels of risk mastery, which they do. Also, parents who have made an alternative vaccination decision and postponed or refused a vaccination are likely to have a high level of risk mastery; regardless of their experience of pressure, they have made a decision that goes against the norm which demonstrates their ability to mediate the vaccination risks their child faced. The group of pressured acceptors, however, reported the lowest mean mastery levels. This group may represent parents who would have liked to

make an alternative vaccination decision, but were unable to in the face of mandates or physician pressure.

Risk as a Predictor of Vaccine Concerns

I speculated that both risk items would be significant predictors of both dimensions of vaccine concerns (regulations and safety). Ordinary least squares (OLS) regressions of risk awareness on vaccine safety concerns and vaccine regulation concerns, considered separately, were non-significant. Health risk mastery, however, was a significant predictor of both vaccine safety and regulation concerns (Figure 3.1). Mastery decreases vaccine related concerns; for every one-unit increase in risk mastery, vaccine safety concerns decrease by .16 units, $F(1, 241)=5.24, p<.05$. Similarly, each additional unit of risk mastery decreases vaccine regulation concerns by .15 units, $F(1, 241)=4.84, p<.05$. Risk mastery explains only a small proportion of the variance in each vaccination concern domain, however. (In each model $R^2=.02$.)

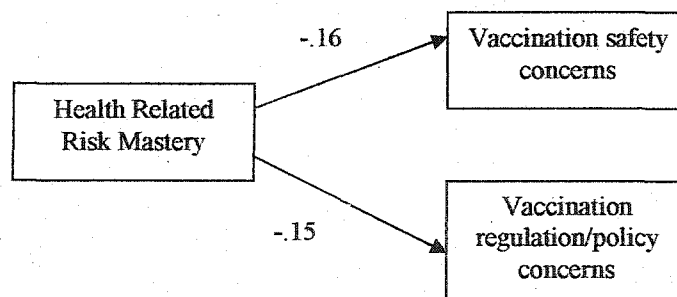


FIGURE 3.1 Risk Mastery as a Predictor of Vaccine Concerns

Mistrust and Vaccine Uptake

Beck's theory of risk society posits that while individuals are increasingly aware of the risks present in modern society, they also are also mistrustful of expert systems of knowledge and more cognizant that there is no clear agreement within scientific or governmental realms about the actual risks individuals face. At the same time, however, the nature of modern risks requires that individuals rely on the knowledge of experts. Knowledge is specialized and no one person can have all the knowledge required to make fully informed decisions about all the health related risks they face. So we all must rely to some extent on the risk assessments of experts, even if those assessments may be contradicted by the evidence presented by other experts. To explore the phenomenon of parental questioning and refusal of immunization, and to assess the fit of Beck's theory to this manifestation of questioning, I have examined the relationship of mistrust and skepticism of government and science to vaccine uptake. I hypothesized that the dependent condition of vaccine uptake (ever or never refusing or postponing) will be related to both types of skeptical attitudes (mistrust of science and medicine and mistrust of government and corporations) such that respondents who make alternative vaccination decisions will be more skeptical than those who do not. I also speculate that pressured respondents will express more mistrust on both scales than will non-pressured respondents.

The hypothesis that ever postponing/refusing respondents will express more mistrust finds mixed support. Respondents choosing to postpone or forego vaccination demonstrate significantly more mistrust of science and medicine ($M=.19$, $SD=.96$) than do those who do not postpone/forego ($M=-.06$, $SD=.76$), $t(248)=-1.98$, $p<.05$. There was no significant difference in mistrust of government and corporations, however, between respondents who had ever refused/postponed and those who never refused/postponed.

The perception of pressure is significant in both mistrust domains. One-way ANOVA results of the mistrust of science and medicine composite variable by decision-

pressure category show significant mean differences, $F(3, 256)=5.17, p<.01$. This conclusion is the result of two significant pair wise contrasts: pressured ever refusing/postponing respondents expressed greater mistrust of science and medicine ($M=.634, SD=1.17$) than did non-pressured refuser/postponers ($M= -.078, SD=.685$), $p<.01$; and pressured refusers/postponers expressed significantly more mistrust than non-pressured never refusing/postponing parents ($M= -.076, SD=.763$). There are also significant mean differences in mistrust of government and corporations by decision-pressure groups, $F(3, 246)=2.61, p<.10$. The significant pairing accounting for this result is between pressured refuser/postponers and non-pressured acceptors. Pressured refuser/postponers are more significantly more mistrustful of government and corporations ($M=.486, SD=.922$) than are non-pressured acceptors ($M= -.071, SD=.909$), $p<.05$.

Mistrust as a Predictor of Vaccine Concern

I postulated that mistrust of science and medicine is likely to be related to vaccine concerns. If a parent is suspicious of medicine, it is plausible to assume that he or she is going to be mistrustful of vaccines, the products of science and medicine. Similarly, if a parent is mistrustful of corporations and government, they are also going to have concerns about vaccination mandates. In short, I hypothesize that both mistrust domains will be significant predictors of both subsets of vaccination concerns. OLS regression results demonstrate that each additional unit of mistrust in science or medicine increases vaccination safety concerns by .50 units ($p<.001$), controlling for mistrust or skepticism of government and corporations. Similarly, increasing mistrust in government and corporations by one-unit increases vaccination safety concerns by .17 units ($p<.01$), net of science/medicine mistrust. These two mistrust variables explain 28% of the variance of vaccine safety concerns. (See Figure 3.2)

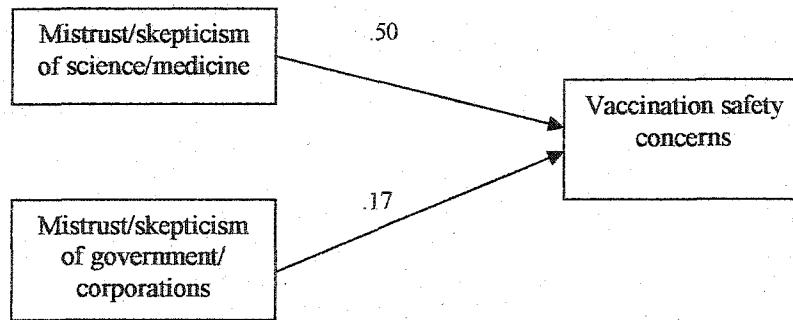


FIGURE 3.2 Direct Effects Mistrust Domains on Vaccine Safety Concerns

A one unit increase of mistrust in science/medicine increases vaccine regulation concern by .53 units ($p < .001$), in the presence of mistrust of government and corporations. Further, each additional unit of mistrust in government or corporations increases vaccine regulation concern by .15 units ($p < .05$), controlling for mistrust of medicine and government. These two variables account for 29% of the variance in vaccination regulation concerns.

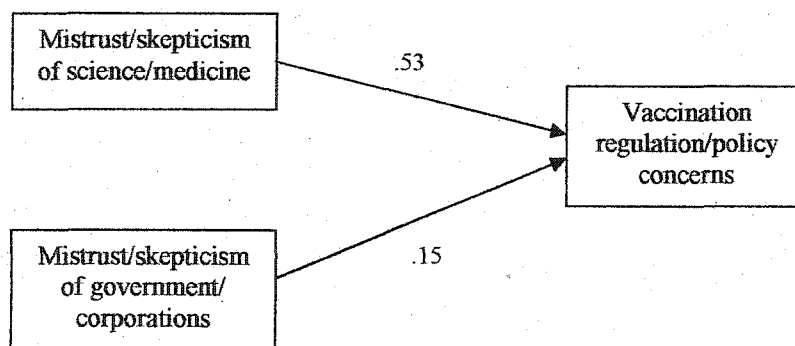


FIGURE 3.3 Direct Effects of Mistrust Domains on Vaccine Regulation/Policy Concerns

It is important once again raise the issue of reverse causation. While it is assumed in these analyses that mistrustful attitudes are antecedent to vaccine-related concerns, this may not be the case. It is entirely plausible that parental mistrust of science, medicine,

government, or corporations could be influenced by their concerns about vaccine policies, regulation, or safety. With the cross sectional data presented here, it is not possible to determine the temporal ordering of mistrustful attitudes and immunization concerns. Since I have extended Beck's theoretical model about risk society to the phenomenon of parental vaccine postponement and refusal, I am assuming that mistrust elements predate vaccine attitudes, at least analytically if not in practice.

Use of and Attitudes about Alternative Medicine

Are parents who support an alternative medical orientation or who use alternative and complimentary medicine more likely to forego or postpone vaccinating their children? In addition, do parents' views and use of alternative medicine relate to their concerns about vaccination? Evidence indicates that alternative and complimentary medical modalities are becoming more popular in pediatric health care (Lee and Kemper 2000; Perrin and Kemper 2000). Perrin and Kemper (2000) report that only 30% of their sample of chiropractors recommended vaccinations. Less than 20% of homeopaths and 13% of naturopaths surveyed by Lee and Kemper (2000) recommended vaccinations. Not recommending vaccination is distinct from advocating against vaccination. Yet, alternative medical orientation appears to be related to parental skepticism about vaccine safety and efficacy (Gellin et al 2000).

In the present study I have sought to determine if vaccine postponing or refusing parents are more likely have alternative medical views, and if there are more likely to bring their children for alternative medical care. I hypothesized that ever postponing/refusing parents would have a more alternative medical orientation and would use alternative medicine more often than never postponing/refusing parents. These hypotheses found no support in these data. There was no significant relationship between vaccine refusal/postponement and alternative medicine use, nor where there significant differences

between ever and never postponer/refusers in their view of alternative medicine. But what of those who felt pressured about their vaccination decisions? Results of a one-way ANOVA reveal no significant differences in views of alternative medicine by category of decision-pressure. There was also no relationship between decision-pressure group and alternative medical use.

But if alternative medical orientations (in beliefs or usage) are not related to vaccine uptake or the combination of decision and pressure, is alternative medical orientation related to concerns about vaccination? OLS regression of the two types of vaccine safety concerns on alternative views of alternative medicine and alternative medicine use reveal that both views and use of alternative medicine are significant predictors of increased vaccine safety concerns (Table 3.3). Respondents using alternative medicine have predicted vaccine safety concerns .538 units higher than non-users, at any given value of alternative medicine views. Every one-unit increase in alternative medicine view increases vaccine safety concern by .184 units, net of alternative medicine use. A similar relationship holds for both views and use of alternative medicine as significant positive predictors of vaccination regulation or policy concerns. Every one-unit increase in the respondents' view of alternative medicine increases vaccine regulation and policy concerns by .185 units, in the presence of alternative medical use. Users of alternative medicine have vaccine regulation concerns that are .448 units higher than non-users, net of the effect of alternative medicine view.

TABLE 3.3 Regression of Vaccine Safety Concerns on Alternative Medical Views and Use (N=217)

	Vaccine safety concern <i>b</i> (S.E)	Vaccine regulation concerns <i>b</i> (S.E)
Use of alternative medicine (0=no)	.635 (.158)***	.506 (.158) **
View of alternative medicine	.184 (.085)*	.185 (.086)*
Constant	-.096	-.058
	$R^2=.1125$	$R^2=.0846$

* $p<.05$, ** $p<.01$, *** $p<.001$

Summary

The results presented here indicate that while vaccination-related concerns are not shared by the majority of parents, there is a sizable proportion of parents who expressed some vaccination questions or concerns. While most parents are able to have their questions answered, questioning vaccination is significantly related to uptake behaviors. Furthermore, these results demonstrate that there is a group of parents (both vaccinating and not) who feel pressure on their decisions.

There are also differences in social status and the experience of support that are related to either vaccination uptake or uptake under pressure. Education is related to more vaccine questioning and to a greater likelihood of postponement or refusal. By contrast, minority status is associated with less vaccine questioning and a greater likelihood of vaccine acceptance. Social support also contributes to our understanding of parental questioning of medical practices, their experience of pressure, and their acceptance or refusal of vaccination. Finally, pressure is related to parental mistrust and risk related mastery, which are also related to vaccine questioning.

My next step is to examine how these relationships play out in a multivariate context. It is to these analyses that I turn in the next chapter.

CHAPTER 4

RESULTS TESTING CONCEPTUAL MODEL

Overview

The previous chapter presented descriptive statistics investigating the interrelations between variables of interest. The main intent of that chapter was to provide an overview of the characteristics of parents making alternative vaccination decisions, and to determine if there are any bivariate relationships between parental characteristics and vaccination decisions (with and without the context of pressure). In the current chapter I will attempt to move beyond the descriptive analyses and test the conceptual model outlined earlier (Figure 2.1). This model is informed by Ulrich Beck's theory of the risk society, applying his ideas to the phenomenon of vaccine questioning and resistance. In this model I postulate that parental awareness of health related risk and perceived health risk mastery, along with mistrust of expert systems of knowledge, will influence acceptance of pediatric vaccinations. Given earlier analyses indicating important differences in uptake behaviors in the presence of pressure to vaccinate, the following analyses consider the four decision group membership and behavioral outcome groups as the dependent variable. First I test for effects of risk and mistrust elements on vaccine decision-pressure, independent of one another and demographic factors. In addition I explore if there are effects of risk and mistrust that influence vaccine uptake through parents' concerns about vaccines. In other words, do risk and mistrust variables predict vaccine concerns, which in turn will influence vaccine uptake behaviors in the context of pressure from doctors, schools, and/or daycare providers? Finally, I examine if social support, education, and minority status will moderate the relationship between vaccine questioning and vaccine uptake. That is, is the

strength and/or the direction of the association between vaccine questioning and uptake under pressure different across different levels of education, minority status, and social support? I test each of these questions in this chapter.

If Beck's contentions about risk society find an evidentiary base in vaccine resistance and refusal, we would expect to find that vaccine uptake (with or without pressure) is influenced by individuals' health related risk awareness and mastery, and their level of skepticism or mistrust of expert knowledge. The nature of the hypothesized relationships are that 1) as awareness of health related risks increases, vaccine postponement or refusal will be more likely, regardless of pressure; 2) as respondents' health-related risk mastery increases, parents will be more likely to resist immunization for their children (particularly when pressured); 3) as respondents' skepticism or mistrust of expert systems of knowledge increase, parents will be more likely to resist immunization.

The analyses that follow in this chapter test the effects of these variables on decision-pressure. This is different from previously presented analyses because here I am controlling for the other variables in the model, including social support and socioeconomic status. In addition, I am including two measures of alternative medical orientation as control variables. Even though Beck's theory does not deal with this concept, I am including this for two reasons. First, the literature suggests that alternative medical orientation is related to parental skepticism about vaccinations. Second, this relationship was supported in the analyses presented in the previous chapter. Ordinary least squares regressions of vaccine safety and regulation/policy concerns on views about and use of alternative medicine revealed that orientation to alternative medicine is a significant predictor of both types of vaccine relation concerns. Users of pediatric alternative medicine have greater safety concerns than do non-users, and more favorable views of alternative medicine are associated with greater safety concerns. Similar relationships were found for vaccination regulation and safety concerns: users of alternative medicine were

more concerned about regulations and policies than were non-users, and attitudes about alternative medicine were positively related to greater regulation and policy concerns. Thus, I want to examine the relationships between mistrust and risk elements controlling for alternative medical orientation.

Another important addition to the models being tested is the creation of a new composite vaccination questioning or concern variable. In previous analyses, vaccination-related fears and concerns were measured by two variables pertaining to two distinct constructs: vaccine safety and regulation/policies. This distinction was conceptually important and practically revealing. As might be expected, however, the two variables are highly correlated with one another ($r=.75, p<.0001$). Under conditions in which two or more independent variables have a strong linear relationship, estimates of coefficients in regression models become unstable and less reliable, an undesirable outcome. I therefore combined the two into a new composite measure of vaccine concerns. (Bivariate and multivariate analyses not presented here showed that OLS regressions of separate vaccine safety concerns on predictors yielded similar results as regressions with the new composite vaccine concerns variable.)

Before presenting the results of the analyses, it is important to stress that the combination of decision and pressure (the dependent variable in these analyses) is an imperfect measure. One flaw is that I am unable to determine when the pressure occurred. It may be that parents didn't perceive pressure at the time they were making vaccination decisions, but may have retrospectively assessed conversations with physicians or school/daycare administrators as pressuring their actions. To the extent that parents perceive pressure, this perception may be influencing vaccination behaviors, regardless of whether the pressure was retrospective or in the moment. Another limitation of the measure is that pressure could come from doctors, schools, or daycare providers, and due to the small sample size, I am unable to run separate analyses for each of these types of

pressure. There may be differences in parents' perceptions of pressure and the influence it has on their decisions depending from whence it comes. This should be addressed in further studies.

Limitations notwithstanding, I believe that the perception of pressure is important. Whether parents actually experienced pressure is not as critical as their *perception* of pressure. A parent who is supportive of vaccination may not perceive the doctor's discussion of the benefits of immunization as forceful or demanding; instead, they may view the discussion as supportive of their beliefs and further evidence supporting their decision. Parents who have lingering vaccination doubts or concerns, though, may interpret the physician's presentation of vaccination information as forceful or oppositional to their thoughts and contrary to their decisions.

Further, I contend that there will be important differences between decision-pressure groups in their beliefs and attitudes. Specifically, I would assert that the greatest differences will appear between the pressured versus not pressured groups, regardless of decisions about vaccination. This is because the groups of parents who have experienced pressure, whether vaccinating or not, may be more vulnerable to pressure. While I cannot determine from these data whether pressured parents are more undecided than non-pressured parents about whether or not to vaccinate, I do know that they are perceiving pressure and that there is a significant difference in concerns (both in the specific domains of safety and regulation, and in the aggregate measure) between decision/pressure groups, with pressure groups expressing more vaccine-related concerns regardless of decision.

Multinomial Logistic Regression

Multinomial logistic regression allows us to predict the relative odds of a respondent being in one category of the four possible decision/pressure groups (non-pressured ever postponing/refusing, pressured ever postponing/refusing, non-pressured

acceptors, and pressured acceptors) based on the influences of the independent variables. The reference category is the non-pressured acceptance category. This is the category into which most parents (in the sample and population) will fall. These are parents who support vaccination and are not questioning vaccination to the extent of altering the recommended vaccination schedule. In essence, then, this category is the normative category. For the sake of interpretive clarity, I often refer to the reference category as the norm.

The relative risk ratio is the amount by which the predicted odds of being in each of the three comparison groups (compared with the norm) are multiplied for every one-unit increase in the independent variable, if all the other independent variables are held constant. When interpreting the relative risk ratios in multinomial logistic regression, odds greater than one increase the likelihood of a subject being in one category (relative to the reference category) and odds less than one decrease the odds. Alternately we can discuss the percentage increase or decrease in the odds of being in one category as opposed to the reference category.

Independent Effects of Risk and Mistrust on Vaccination Behaviors

Table 4.1 shows the independent effects of risk and mistrust variables on decision-pressure, controlling for alternative medical orientation, social status, and support variables. The overall model is significant (LR $\chi^2=64.20, p<.001$), with a pseudo R^2 of .1668. Each additional unit of risk mastery significantly decreases the odds of ever postponing or refusing with no pressure (relative to the norm) by 42% (multiplies the odds by .578), net of other variables. Education is also significant: each additional unit of education increases the odds of non-pressured postponement or refusal (relative to non-pressured acceptance) by 39%, in the presence of other variables.

Table 4.1 Independent Effects of Hypothesized Predictors on Decision-Pressure Multinomial Logistic Regression, Relative Risk Ratios (S.E.) (N=201)

	Dependent Variable: Decision-Pressure Group		
	Non-Pressured Postponer/Refuser	Pressured Postponer/Refuser	Pressured Acceptor
Risk Awareness	1.72 (.609)	.643 (.241)	1.10 (.425)
Risk Mastery	.579 [†] (.177)	1.48 (.663)	.406 ^{**} (.139)
Mistrust in Science or Medicine	.885 (.297)	1.38 (.498)	.442 [†] (.206)
Mistrust in Government or Corporations	.919 (.277)	1.74 (.675)	.997 (.428)
Use of Alternative Medicine (0=no, 1=yes)	.590 (.387)	1.31 (.919)	.238 (.261)
Views of Alternative Medicine	1.02 (.320)	.770 (.352)	.592 (.251)
Education	1.39 [†] (.255)	1.30 (.304)	.995 (.219)
Minority Status (0=no, 1=yes)	.327 (.262)	.690 (.607)	1.81 (1.24)
Social Support from Doctors	1.74 (.715)	.681 (.211)	.393 ^{**} (.122)
Social Support from Family and Friends	.686 (.218)	.482 [*] (.178)	.815 (.318)
Non-Vaccination Network	.938 (.480)	5.03 ^{**} (2.98)	2.66 (1.61)
LR $\chi^2 = 64.20^{***}$			
Pseudo R ² = .1668			

NOTE: Reference category is Never Refused or Postponed/No Pressure

[†] $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$

Two social support dimensions significantly influence the odds of pressured postponement/refusal. (It is important to note again that the direction of influence could be in the other direction; yet decision-pressure is the dependent variable specified in the conceptual model.) Each additional unit of support from family and friends decreases the odds of pressured postponement/refusal by nearly 52%, relative to the norm and in the presence of other variables. Membership in a network of others making alternative vaccination decisions increases the odds of pressured refusal or postponement by 402%, net of other variables.

Finally, there are independent effects of risk mastery and mistrust in science and medicine on pressured acceptance. Each additional unit of health related risk mastery decreases the odds of pressured vaccine acceptance (rather than non-pressured acceptance) by 59%, all other things being equal. Similarly, each additional unit of mistrust in science and medicine decreases the odds of pressured acceptance (relative to the norm) by nearly 56%, controlling for other variables. Physician support is also a significant predictor of pressured acceptance relative to the norm, decreasing the odds of pressured acceptance by nearly 61% for each additional unit of physician support in the presence of other variables.

Thus, there is mixed support for the hypothesis that mistrust and risk elements have independent effects on decision-pressure. My hypothesis that health risk awareness would be related to vaccine postponement/refusal finds no support. Health risk mastery, however, is significantly related to decreasing the odds of both non-pressured postponement/refusal and pressured acceptance. Mistrust in science and medicine is significantly associated with decreased odds of pressured acceptance; yet, mistrust in government or corporations was not significant in predicting the odds of any decision-pressure group relative to the norm.

There are a few possible explanations why there were no independent effects of health risk awareness and mistrust of government and corporations on decision-pressure. One possibility is that Beck's theory does not fit the phenomenon of vaccination questioning and resistance. Since, however, other elements contained in the theory were significant, this is not the most likely reason for the non-significant results. It may be that the items I have devised are not sufficiently valid measures of the constructs. This will need to be examined before future research is undertaken. Another possible explanation relating to health risk awareness may be that measuring *general* health risk awareness accounts for the lack of significance. It may be that general health risk awareness does not translate into decision making about a *particular* set of medical recommendations such as vaccinations.

Because of this latter possibility, I sought to examine if there is a relationship between elements of risk society that operate through vaccination concerns, a more specific construct than general health risk awareness, and one more closely related to the dependent variable. It is to this analysis that I now turn.

TABLE 4.2 Indirect Effects of Hypothesized Predictors on Decision-Pressure, Multinomial Logistic Regression, Relative Risk Ratios (S.E.)

	MODEL 1 (N=201)			MODEL 2 (N=188)		
	Non-Pressured Postponer/Refuser	Pressured Postponer/Refuser	Pressured Acceptor	Non-Pressured Postponer/Refuser	Pressured Postponer/Refuser	Pressured Acceptor
Risk Awareness	1.72 (.609)	.643 (.241)	1.10 (.425)	1.77 (.640)	.380† (.204)	2.31 (1.25)
Risk Mastery	.579† (.177)	1.48 (.663)	.406** (.139)	.550† (.175)	1.32 (.712)	.270** (.117)
Mistrust in Science or Medicine	.885 (.297)	1.38 (.498)	.442† (.206)	.815 (.296)	.540 (.312)	.453 (.269)
Mistrust in Government or Corporations	.919 (.277)	1.74 (.675)	.997 (.428)	.771 (.251)	1.13 (.689)	.395 (.231)
Use of Alternative Medicine (0=no, 1=yes)	.590 (.387)	1.31 (.919)	.238 (.261)	.626 (.415)	1.61 (1.34)	.385 (.436)
Views of Alternative Medicine Education	1.02 (.320)	.770 (.352)	.592 (.251)	.966 (.315)	.537 (.326)	.489 (.231)
Minority Status (0=no, 1=yes)	1.39† (.255)	1.30 (.304)	.995 (.219)	1.25 (.234)	1.33 (.389)	.979 (.250)
Social Support from Doctors	.327 (.262)	.690 (.607)	1.81 (1.24)	.157† (.171)	1.99 (2.03)	1.18 (1.01)
Social Support from Family and Friends	1.74 (.715)	.681 (.211)	.393** (.122)	1.53 (.652)	.774 (.353)	.348** (.141)
Non-Vaccination Network	.686 (.218)	.482* (.178)	.815 (.318)	.695 (.227)	.788 (.366)	.859 (.396)
Vaccine Concerns	.938 (.480)	5.03** (2.98)	2.66 (1.61)	.856 (.457)	2.41 (1.76)	1.99 (1.38)
				1.57 (.552)	7.92*** (4.67)	2.59† (1.46)
		LR $\chi^2 = 64.20^{***}$ Pseudo R ² = .1668			LR $\chi^2 = 89.51^{***}$ Pseudo R ² = .2519	

NOTE: Reference category is Never Refused or Postponed/No Pressure

† $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$

Indirect Effects of Risk and Mistrust Elements

Table 4.2 displays the results of the multivariate multinomial logistic regression including vaccination concern as an independent variable. Model 1 replicates the results from Table 4.1; Model 2 examines the effects of the hypothesized predictors in the presence of vaccine concerns. As I described above, the two composite variables that operationalize the two dimensions of vaccine concerns, safety and regulation or policies, were very highly correlated ($r=.75$). Maintaining both these variables in the multivariate analyses created problems associated with multicollinearity. To address this, a new composite variable was created from all the vaccination items. This new variable masks the distinctions between separate dimensions of vaccine concerns that I was able to tease out in the descriptive summaries in the previous chapter; but since the finer grained differences between types of vaccination concerns are not necessary in the overall model, this solution is acceptable. This new composite variable is the vaccination concern variable used in these analyses.

As with the previously discussed multinomial logistic regressions, the reference category is the normative group of respondents who accepted vaccination and did not perceive pressure. This multivariate model is highly significant ($p<.001$) with a pseudo R^2 of .2519. As expected, this is an increase from the model in Table 4.1 ($R^2=.1668$). When added as a possible predictor of decision-pressure, vaccine concern is significant in predicting an increase in the odds of experiencing pressure, regardless of vaccine uptake behavior. Each additional unit of vaccine concern increases the odds of postponing or refusing a vaccination under pressure by 692%, relative to the norm, controlling for other variables. Every one unit increase in vaccine concerns also increases the relative odds of pressured acceptance by 159%, net of other variables. As parents have more concerns about the immunizations their children might receive, they are also more likely to perceive pressure on their decisions.

There is also evidence of mediating and suppressor effects of vaccine concerns. First, while risk awareness did not have a significant direct association with decision-pressure, it has a significant effect when vaccine concern is controlled. Thus, vaccine concern suppresses the relationship between health related risk awareness and pressured refusal or postponement. Independent of vaccine concerns, risk awareness has a negative effect on refusal or postponement. Each additional unit increase in health related risk awareness decreases the odds of postponing or refusing vaccination under pressure (versus accepting with no pressure) by 62% (multiplies the odds by .38), net of other variables.

In this elaborated model, health risk mastery remains significant. The odds of ever refusing/postponing with no pressure (relative to the norm) decrease by 45%, in the presence of vaccine concerns, with each additional unit increase in health risk mastery. This is a change from the 42% decrease in the odds of non-pressured refusal/postponement when the relationship is examined without the presence of vaccine concerns. Thus, the addition of vaccine concerns strengthens (albeit slightly) the negative effect of mastery on the odds of ever postponing/refusing vaccination without pressure. A similar effect of the presence of vaccination concerns on the relationship between health related risk mastery and the odds of pressured acceptance is evident. In the presence of vaccine concerns, each additional unit of health risk mastery is associated with a 73% decrease in the odds of accepting vaccination under pressure (relative to the norm and net of other variables), a change from 59% when vaccination concerns are not controlled.

Vaccine concern mediates the effect of mistrust of science and medicine on the odds of pressured acceptance. While in Model 1, mistrust in science and medicine significantly decreased the odds of pressured acceptance by nearly 56%, this relationship becomes non-significant in the presence of vaccine concerns.

The only social status variable that is significantly associated with decision-pressure when controlling for vaccine concern is minority status. This is a change from the

model not containing vaccine concerns. When vaccine concerns are controlled, minority status becomes significant, with minority respondents less likely to ever postpone or refuse vaccinations with no pressure. In the presence of vaccine concerns, we see that minority parents are 84% less likely to be non-pressured postponer/refusers than are non-minority parents, relative to the norm and in the presence of controls. Thus, it appears that vaccine concerns have a suppressor effect on what would otherwise be a negative relationship between minority status and vaccine postponement/refusal. Additionally, the independent effect of education (increasing the odds of non-pressured refusal/postponement) observed in Model 1 disappears when vaccine concern is added. Thus, the effect of education on decision-pressure operates through the mediating influence of vaccine concern.

In the independent effects model (Table 4.1 and Model 1, Table 4.2) each additional unit of social support from physicians significantly decreased the odds of pressured acceptance by nearly 61%, net of other variables, relative to the norm. The addition of vaccine concerns slightly strengthens this association: controlling for vaccine concerns and other variables, each additional unit of physician support decreases the odds of pressured acceptance by 65%.

Turning to the other support domain, once vaccine concerns are controlled, support from family and friends is no longer significant. Vaccine concerns, therefore, mediate the effect of family and friend support on the odds of ever refusing/postponing under pressure. In other words, the reduced odds of pressured postponing or foregoing among those with higher support is explained by the negative effects of support on vaccine concerns.

Finally, vaccine concern mediates the association between alternative vaccine decision network membership and pressured postponement or refusal. Whereas non-vaccination network membership significantly increased the odds of pressured postponement/refusal when vaccine concern is not controlled, once concern is added to the model, the effect of network membership is no longer significant. Thus, the effect of

belonging to a group of other parents who do not vaccinate on vaccination behaviors operates through its positive relationship with vaccination concerns.

Assessing Conditional Relationships

My conceptual model posited that the relationship between vaccine concerns and uptake would be conditional upon social support, education, and minority status variables. I ran a series of models to test for significant interactions between 1) vaccine concern and social status variables and 2) vaccine concerns and social support variables.

Conditional Effects of Education

In Model 1 of Table 4.3, we see evidence of a conditional relationship: the interaction of education and vaccine concerns is significant, increasing the odds of pressured acceptance relative to the norm. In order to assess the direction of the interaction, I re-ran the same multinomial logistic regression model separately for respondents who have an education level below the mean and for those with an education greater than or equal to the mean (not shown). Education was measured as a categorical variable with seven categories, but it is treated here as a measurement level variable. The mean is 5.06, and category 5 is “completed at least some college.” Splitting the sample at the mean of education and running separate multinomial regressions allowed me to compare the relative risk ratios across the models.

Vaccine concerns are a significant predictor of vaccine uptake behavior for respondents with greater than the mean education. Each additional unit of vaccine concern increases the odds of *pressured postponement/refusal* by a relative risk ratio of 1410, relative to the norm, all other things being equal. When this ratio is compared to the relative risk ratio of vaccine concerns on the odds of pressured refusal for low education respondents (6.07), it is clear that the magnitude of the effect of vaccine concern on pressured postponement/refusal is far greater for higher education parents.

Vaccine concerns also have a significantly greater effect on the odds of *pressured acceptance* for higher education parents. Among the higher educated sample, each additional unit of vaccine concern increases the odds of pressured acceptance by 671%, relative to the norm and net of other variables. This relationship does not appear, however, for parents in the lower education group; in this group, there is no significant effect of vaccine concern on uptake under pressure.

When the interaction of education with vaccine concern is examined, a picture develops in which pressure becomes more salient with more education. Concern is more likely to get translated into the experience of pressure among the more highly educated. Perhaps higher SES parents with more vaccine concerns are more aware of or sensitized to societal pressured to vaccinate. On the other hand, respondents with more education could be more likely to perceive pressure as a result of expressing their vaccine questions.

TABLE 4.3. Multivariate Multinomial Logistic Regression of Decision-Pressure on Model Predictors, Including Education and Minority Status Interaction
 Terms: Relative Risk Ratios (S.E.) (N=188)

	Model 1			Model 2		
	Non-Pressured Postponer/Refuser	Pressured Postponer/Refuser	Pressured Acceptor	Non-Pressured Postponer/Refuser	Pressured Postponer/Refuser	Pressured Acceptor
Risk Awareness	1.75 (.630)	.416 [†] (.219)	2.05 (1.11)	1.78 (.650)	.387 [†] (.215)	2.83 [†] (1.58)
Risk Mastery	.572 [†] (.182)	1.25 (.653)	.288** (.126)	.568 [†] (.181)	1.39 (.775)	.280** (.125)
Mistrust in Science or Medicine	.796 (.290)	.586 (.350)	.405 (.256)	.820 (.297)	.509 (.309)	.544 (.350)
Mistrust in Government or Corporations	.768 (.253)	1.53 (.701)	.417 (.230)	.766 (.251)	1.09 (.695)	.314 [†] (.202)
Use of Alternative Medicine (0=no, 1=yes)	.641 (.424)	1.46 (1.25)	.406 (.450)	.647 (.430)	1.79 (1.54)	.667 (.758)
Views of Alternative Medicine	.956 (.312)	.462 (.292)	.475 (.234)	.952 (.311)	.473 (.298)	.462 (.246)
Vaccine Concerns	1.93 (2.47)	.687 (1.32)	.104 (.179)	1.61 (.589)	10.15*** (6.52)	3.46 [†] (2.16)
Education	1.26 (.237)	1.01 (.394)	.897 (.244)	1.25 (.236)	1.38 (.411)	1.01 (.275)
Minority Status (0=no, 1=yes)	.159 [†] (.173)	1.83 (1.94)	1.03 (.899)	.149 [†] (.163)	2.23 (2.52)	1.02 (.950)
Social Support from Doctors	1.44 (.604)	.796 (.365)	.291** (.126)	.139 (.599)	.612 (.290)	.221*** (.104)
Social Support from Family and Friends	.695 (.232)	.719 (.341)	.756 (.356)	.669 (.221)	.737 (.348)	.657 (.317)
Non-Vaccination Network	.881 (.469)	2.65 (2.01)	2.50 (1.82)	.859 (.458)	2.48 (1.84)	2.10 (1.59)
Education*Vaccine Concerns	.963 (.224)	1.60 (.590)	1.83 [†] (.564)			
Minority Status* Vaccine Concerns				.672 (1.17)	.332 (.463)	.027** (.036)
		LR $\chi^2=89.51$ *** Pseudo R ² =.2519			LR $\chi^2=98.14$ *** Pseudo R ² =.2762	

NOTE: Reference category is Never Refused or Postponed/No Pressure [†] $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$

Conditional Effects of Minority Status

Model 2 of Table 4.3 presents the multinomial logistic regression results of the interaction of minority status multiplied by vaccination concerns in a model that also includes risk, mistrust, alternative medicine, vaccine concerns, support, and education independent variables. I hypothesized that there will be a smaller impact of vaccine concerns on postponement/refusal for minority respondents and/or a greater impact of vaccine concerns on pressured acceptance. This is because minority respondents may have a more difficult time accessing stable, reliable, and affordable health care than non-minority respondents, and may therefore be more desirous of preventative medicine and other interventions. Perhaps minority respondents' concerns about obtaining health care may supercede their concerns about vaccination, making these parents less likely to raise troubling or problematic issues about vaccinations with their health care providers, thereby reducing their experience of pressure. There are also likely to be power issues at work; minority respondents may have less access to cultural capital and other resources that would allow them to enact alternative vaccine decisions in the face of pressure from authority figures.

There is a significant interaction of minority status with vaccine concerns, indicating that for minority respondents, each additional unit of vaccine concern reduces the odds of pressured acceptance by 97%, relative to the norm and in the presence of other controls. To further explore the direction of the relationship I re-ran the model separately for minority and non-minority respondents (not shown). Due to the low number of minority respondents, relative risk ratios were not calculable. Multinomial logistic regression uses maximum likelihood estimation to derive parameters, and this technique requires a large enough sample size for each combination of independent variables; my sample size of minority respondents was insufficient, precluding me from any more

substantive interpretation of the differences between groups. I therefore only discuss the model for non-minority respondents.

Vaccine concerns have a significant influence on pressured postponement/refusal and pressured acceptance for non-minority respondents. Each additional unit of vaccine concern multiplies the odds of pressured postponement/refusal by 12.40 (increases the odds of 1140%), net of other variables. Additionally, each unit of vaccine concern increases the odds of pressured acceptance by 223%, relative to the norm and all other things being equal. These results mirror the conditional effects of education, contributing to the conclusion that the dynamics of privilege and social power heighten the perception or susceptibility to pressure in the context of concerns, regardless of uptake behaviors. While I was not able to examine the relationship between vaccine concern and uptake behavior in the context of pressure for minority respondents, a comparison of results for the non-minority sample with the results of the entire sample (Model 2, Table 4.2) confirms the greater impact of vaccine concerns on pressured acceptance and pressured refusal/postponement among non-minority respondents. This supports my hypothesis that there would be a smaller impact of vaccine concerns on refusal/postponement for minority respondents; but is contrary to the hypothesis that there would be a greater impact of concerns on pressured acceptance for minority parents.

Conditional Effects of Social Support

The final piece of testing the conceptual model involved examining the possibility of a conditional effect of social support on the relationship between vaccine concern and decision-pressure group. I ran three models each testing (separately) the interaction between vaccine concerns and support from doctors, from family and friends, and membership in a non-vaccinating social network. (These analyses are not shown.) None of these interactions were statistically significant.

Summary

What can I conclude, then, on the basis of these tests of the overall conceptual model? When we take into account both vaccination behavior and the experience of pressure from doctors, day care providers, and schools, we see some important trends indicating mixed support for the conceptual model.

Vaccine concerns are an important and significant factor increasing the odds of pressured refusal/postponement and pressured acceptance. This influence is central, as it mediates or suppresses the effects of several other variables on decision pressure.

Health risk awareness has no independent effects on decision pressure as was posited by the conceptual model. Yet, vaccination concerns have a suppressor effect on this relationship. In the presence of vaccine concerns, health risk awareness lowers the odds of pressured refusal/postponement. While one of my alternative hypotheses stipulated that awareness of risks could increase the likelihood of making an alternative vaccination decisions, it appears that the opposite is true: in conjunction with concerns about vaccination, which are a specific type of risk awareness and significantly increase the odds of pressured refusal and acceptance, general health risk awareness decreases the odds of a pressured alternative vaccination decision.

Health risk mastery is significantly and independently associated with decreased odds of non-pressured postponement/refusal and pressured acceptance. These relationships intensify in the presence of vaccine concerns. When parents perceive that they have the ability to intervene in the risks their families face, even when they also have vaccine concerns, they are less likely to be pressured into vaccine acceptance or to refuse vaccination even with no pressure.

Mistrust in science and medicine significantly and independently decreases the odds of pressured acceptance. This relationship is mediated by the presence of vaccine concerns, suggesting that skepticism of expert knowledge in the realm of science and

medicine operates through vaccine concerns in affecting vaccine uptake. The other mistrust domain, mistrust of government and corporations, has no significant influence on decision-pressure. Neither of the alternative medicine variables is related to decision pressure.

Education significantly and independently increases the odds of ever postponing/refusing vaccination with no pressure, but this relationship is mediated by the presence of vaccination concerns. By contrast, there is no independent effect of minority status on decision-pressure, but there is a suppressor effect of vaccine concern. When controlling for vaccine concern, minority status significantly reduces the likelihood of non-pressured refusal/postponement.

While support from friends and family independently decreases the odds of pressured postponement/refusal, and non-vaccination network membership increases the odds of pressured postponement/refusal, these relationships are mediated by vaccination concern. Support from doctors decreases the odds of pressured acceptance, a relationship which becomes stronger when vaccination concerns are present in the model.

Social support variables do not moderate the relationship between vaccine concern and decision-pressure as posited by the conceptual model. Yet, both education and minority status moderate the relationship between vaccination concern and decision-pressure. While vaccine concerns increase the odds of pressured refusal or postponement for both higher and lower education groups, the effect is markedly stronger for the higher education group. Further, vaccine concern significantly increases the likelihood of pressured acceptance, but only for respondents with higher education, the same group we might expect to be better able to withstand pressure. Finally, the likelihood of both pressured refusal/postponement and pressured acceptance are more strongly influenced by vaccine concern for non-minority respondents than for minority respondents.

CHAPTER 5

SUMMARY AND CONCLUSIONS

Overview

In this work, I sought to describe the characteristics of parents who question and oppose immunizations for their children, including describing differences between parents who accept and refuse/postpone immunization under conditions of pressure from doctors, schools, and/or daycare. Understanding how parents' characteristics may differ has implications for social epidemiology and public health policy. A key finding of the work is that when parents have concerns about vaccine safety and/or regulations the odds are high that they will either postpone or refuse vaccination under pressure or will be pressured into acceptance. In order to design effective policy to encourage parents to support vaccination, an aim of health policy, their concerns must be understood and addressed. Without this, parents are likely to perceive more pressure and less support from physicians. Furthermore, the concerns of parents *themselves* must be heard and understood, not just the concerns of parents as they are interpreted by physicians. A more complete understanding on the part of physicians of parents' concerns may also shape doctor-patient encounters, as health care providers may be the ones directly responsible for influencing parents' vaccination decisions leading up to the time when the vaccination would be given.

But this work also makes a contribution to medical sociology, which is related to the second aim of this dissertation: providing an explanation of parental decision refusal/postponement of vaccinations within a framework of risk in modern society. Sociology is concerned with promoting understandings of how social forces and processes influence the behaviors of individuals and aggregates. By explicating how the social status

and perceived social support influence what could otherwise be viewed as an individual decision – whether or not to immunize one’s child – I hope to highlight how individual decisions are always made in a social context and in the presence of social forces. This furthers the tradition of medical sociology, which seeks to uncover the socially constructed and mediated nature of health, including assessment of risks and decision making. On another level, I hope this work contributes to our understanding of life in modern society. If, in fact, we are living in a risk society, then the processes of individual risk assessment and management in the face of skepticism and mistrust of expert knowledge will continue to be features of American life, demonstrated in medical decision making and, undoubtedly, a host of other realms. Indeed, the phenomenon of vaccine questioning and refusal may be part of a broader trend of reaction by some members of society against medical knowledge and intervention as science develops more advanced ways of intervening into nature. With more medical technology individuals may become more aware of the risks that accompany the intended benefits of medical interventions. With greater perceptions of risk, individuals may engage in more personal attempts to mediate harm, including rejecting medicine. Vaccine questioning and refusal may, therefore, be one example of a larger social process.

In what follows below I offer a discussion of the characteristics of vaccine postponing and refusing parents based on findings from the bivariate and multivariate analyses. In order to contextualize the significant multivariate findings, I am including selections of quotes from my qualitative interviews with non-immunizing parents. For the purposes of this dissertation, the main use of the qualitative data was to inform the development of the survey instrument. There is, however, great richness and depth contained in these interviews; they can, therefore, contribute to our understanding of the meaning of the quantitative analyses. I then turn to a discussion of the theoretical

framework and the empirical support found in the tests of the conceptual model. Finally I discuss the limitations of this project and suggest directions for future research.

The Non-Vaccinating Parent and the Dynamics of Privilege

While most parents are supportive of pediatric vaccination, there is a significant portion of the public who are fearful of, suspicious of, or concerned about immunizations. These parents may vaccinate (perhaps as pressured acceptors), or they may delay or entirely forego shots for their children. This study indicates that a combination of social and personal resources influence vaccine related experiences and behaviors. For instance, this research demonstrates how higher education and non-minority status, through the social privileges they carry, operate as conduits for parents to exercise their power in enacting vaccine decisions. Higher education taps parents into vaccine controversies. This is supported by the bivariate finding that parents with more education have more vaccine questions, and are more concerned about vaccine safety and regulations, the two vaccine concern dimensions examined in Chapter 3. With a heightened awareness of potential vaccine related issues, higher educated parents are able to translate their concerns into action. My exploration of the conditional association of vaccine concerns on uptake behavior by education level was significant. While vaccine concerns increase the odds of pressured postponement/refusal for all parents, the association is dramatically stronger for highly educated parents. The benefits of social power in parents' ability to enact their will despite pressure are also evident in the conditional association of vaccine concerns and behavior by minority status. Non-minority parents with vaccine concerns are more likely to be pressured acceptors than they are to be normative vaccine acceptors. (Sample size issues prevented me from examining the relationship for non-minority parents; yet when comparing the whole sample to only non-minority respondents, the effect of vaccine concerns is stronger among non-minority respondents than the entire sample.)

These significant findings would seem to indicate that non-minority and educated parents are better able marshal their status to withstand pressure from authority figures. Evidence of this is found in the experience of Nancy, a Virginia mother of a young son, who was able to enact her decision not to vaccinate after repeated instances of pressure. Nancy recalled feeling pressed into consenting to the hepatitis B vaccination in the hospital after her son was born:

I had no idea that it was going to be such a huge deal that I would say, "No, don't give the vaccine right now. I want to look at that." And I was surprised, the pediatrician spent about a whole hour trying to pressure me into it. And, ah, I just said, "It is hepatitis B, and that is something that is sexually transmitted, and drug users get it. And it has mercury in it! I'm not a drug user, and so I don't have it, so he couldn't possibly get it. So what is the point?" And the pediatrician said, "Well I see your point, but this is what we do." It just didn't make any sense to me. In the most common sense kind of way. I was like, but why? So I said, "No, I still have to do more research." And I wasn't sure until {her son} was about, um, probably about a year old, that I was not ever going to vaccinate him.

Nancy discussed feeling pressured again by another physician in an office visit. She also expressed dissatisfaction with the answers her questions received and her attempts to engage the physician in a dialog about her concerns:

One of the head pediatricians in the office just really let me have it with the whole wanting to vaccinate. I mean, he wouldn't answer any of my questions intelligently. He was just doing the rote, you know, 'you have to do it because you have to do it,' and I'm like, "No I don't. And I have all these other questions and if you can't answer them..." He was not interested. So I ended up buying him some books and bringing them with me [laughs]. And saying, "I wanna be able to discuss this with you in an intelligent way so here are some books you should read." And not books that are all one-sided!

Nancy said the physician "wasn't really happy about" her bringing him the books. Nancy went on to say "that kind of badgering is unethical." To Nancy, her ability to get the physician "to back off" is attributable to her socioeconomic status and the implied threat that may mean to a physician:

And honestly, between you and me, I also think there's a classist thing, a socioeconomic thing going on. The poorer and more uneducated you are, the more likely you are going to be told that you don't have the right to take certain

choices and decisions. And when I walk into the emergency room with my Talbot's purse and my stockbroker husband, and we have insurance and we have money to sue, they basically give us a wide berth. It is not fair... but that is what I see happening, because I do get more stories from other people about how they have been treated, and I kind of look at them and go, "Yep." They don't exactly look like they could afford to sue anybody...

The first pediatrician I talked to, boy, he just wanted to scare the bejesus out of me. He went around saying, "Oh, that could be considered abuse if you don't vaccinate. You can be sued for abuse of your child if you don't vaccinate." And I was looking at him, and I go, "Well, it could be considered a lawsuit if you vaccinate him and he has a reaction." Like, OK, now we understand each other? OK, good, now come off your soapbox, and leave me alone. [Laughs.] He said the abuse word and I said the lawsuit word. They cancel each other out. The L-word. I did say that. It was like, this doesn't make any sense to me what you are saying!

In Nancy's view, her threat of a lawsuit was more credible because of her status. As a result, she was able to get the physician to "back off" and her son was not immunized.

Anna, a young mother of two living in Colorado, addressed how both social class and racial privilege had facilitated a lengthy discussion with her children's doctor about why she did not want to vaccinate. She also, though, raised the issue of how these privileges had not provided her with any protection from an angry exchange with a previous doctor who had called her a "bad mother":

I definitely feel a level of privilege in, especially with that one physician who took such a long time talking to me. Not only was it education but race privilege, I thought of white privilege. And, um, then I spoke to him in a vocabulary that he found accessible and respectable, and he determined that we had done a lot of research ourselves, and we had done the appropriate homework, and we were worthy of spending this amount of time on. It wasn't this, I mean he said that a number of times, "Obviously this hasn't been an off the cuff decision for you, let's talk about this." So, I think the fact that, you know, we have access to the internet, we are of a class that we have a computer in the house that is fast enough that we can click around, you know, gives us a level of information about this and a level of respectability in the health care practitioner's eyes that gave me cultural cache in the setting to get way more than my allotted time. But it didn't protect me in [my hometown], I was that same person, in that doctor's office when he yelled at me and told me I was a bad mother, and kicked me out of his office. He was white, I was white, his receptionist was white, everybody was white, and he, I don't know what class he assumed I was. But I was dressed pretty much as a middle class person. I come across as fairly middle class, and that didn't protect me from his ire, so...

While education and non-minority status may significantly facilitate vaccine refusal/postponement, even in the face of pressure, they are also related to pressured acceptance. At first blush, this may seem like a contradiction to the argument I have advanced above. If more social resources allow parents to assert their will and have their vaccination decisions for their children enacted, then how could greater social resources also relate to pressured acceptance of vaccinations? Pressured acceptance, I contend, may be part of a process where higher status parents are more likely than those with fewer resources to become non-vaccinators. Parents with more resources will be tapped into a wide range of information about vaccinations. They also have characteristics that enhance their ability to raise questions and resist pressure from authorities. Thus, the multivariate finding of a status-moderated significant relationship between vaccine concerns and pressured acceptance may be indicative of a process of gradual movement towards vaccine refusal or postponement. While I did not examine this in the quantitative data, qualitative data reveals patterns of parents stepping down vaccinations, either for the same child or with subsequent children for whom they make different decisions. Since vaccines are administered over a period of several years, parents' decisions about vaccinations are likely to be revisited; as such, a vaccine-accepting parent may become aware of vaccine related controversies and eventually make alternative decisions. Similarly, a vaccine-pressured parent, particularly a first time parent or one who is new to vaccine related controversies, may consent to immunization but later reconsider their decision and become a vaccine postponer or foregoer.

Jean, a Maryland mother, provides an example of how decisions change over time and in light of new experiences and information. Jean has two children who are fully immunized; she was entirely supportive of vaccinations when making the decisions for these children. After becoming aware of vaccine-related controversies because of health concerns with a possibly immuno-compromised third child, Jean stopped immunizing her

daughter and is now skeptical of the side effects of all immunizations. Liz, a Texas mother of four children from the ages of 10 to 17, also discussed how her decision to postpone vaccinations evolved with each child and with her increased familiarity with vaccine debates:

With the eldest, I knew nothing about this controversy. When she was born, my husband was a graduate student...and, uh, she was immunized along the normal timetable. She was a healthy, happy baby. Then we moved to San Antonio, where we had our second child two years later, and I became friends with a woman who happened to be a homeopath. That is where I came in contact with information about the controversy. She had a daughter who was the same age as our first child, and so that is how I got my start. I remember saying to her, when she started asking me questions about it and feeding me information about it, I said, "Well, the medical establishment is an authority in my life, and I'm not sure what it would take for me to go against it." I really do remember that conversation. The eldest was a toddler. Um, but anyway. I developed a network of friends who were alternatively minded, and started becoming familiar with some of the literature that was available to them, um, and typically started worrying about the problem! [Laughs] Our second child was the type who was colicky and would get infections. I was up with him with fevers, and when he had his first DPT immunization, you know I was nervous and probably looking for things, but I didn't like the way he reacted. Um, and so, at that point I decided to delay his immunizations and I don't think we picked up with him until he was almost two. Um, then I decided to go ahead and use that strategy on the younger two, and that is where I came into conflict with a couple of different physicians. And I actually in my file, I actually wrote a very reasonable letter to the first pediatrician, sort of outlining my experience and my debate over the issue and what my decision was, um, and she is the one who ultimately said, "Well, we'll pray for you." And not that that in itself is offensive to me -- I'm a person of religious tradition, but um, it just made it sound to me like she felt like I couldn't make a responsible decision and support that. So, when it was convenient to do so, we changed pediatricians.

As parents are faced with new vaccination decisions over a period of several years, parents who have more access to informational resources may be particularly likely to renovate their decisions with new information. Sarah, an Ohio mother of a young son and daughter, reflected upon how her vaccine decisions were continually revisited in light of new information:

Somehow it doesn't feel that the decision is cut and dried, like the decision was made three years ago, and we're done. And then they came up with Prevnar, then there is always more research, and we were sort of set on what we were going to do, then a friend called, and their child had, he was diagnosed with latent onset autism at age six, and their pediatrician, even, thinks it was caused by the MMR

shot, which is highly unusual. The other pediatricians in the practice won't say that, but their's actually says that because there is some mercury in his bowel... And so anyway, then, you know, you get new information like that, personal things happen to other people, and then you say, "I'm gonna shift again, like I was gonna forego those, now I'm gonna forego these."

The survey data shows that pressured acceptors of vaccination have significantly fewer children than other groups of parents. As there is no reason to think that these parents will be different in their childbearing than other groups of parents, this may be an indication that these parents may be younger and/or having more children in the future. If this pattern of gradual vaccine refusal or postponement continues, we may expect pressured acceptors to become postponers or refusers over time or with subsequent children.

With greater educational and social resources, parents will have more access to a variety of vaccine related information. Though the general issue of information sources was addressed only in the bivariate analyses, these data reveal that parents making alternative vaccination decisions rely more on the advice of chiropractors, naturopaths, and herbalists. As Perrin and Kemper's (2000) evidence suggests, alternative and complimentary practitioners may be less inclined to mention vaccination or they may clearly advocate against it. Though the use of alternative medicine was not a significant predictor of vaccination behavior in the multivariate model, I assert that this may be due to limited statistical power. Thus, I would advocate that the influence of information sources on vaccination behaviors be further explored. There is a clear pattern of support for alternative and complimentary medicine apparent in my qualitative interviews with non-vaccinating parents. Nearly all stated that they use herbal and natural remedies for illnesses, and most had taken their children to a chiropractor, herbalist, or naturopath. In addition, many parents said that they became aware of vaccine controversies from alternative practitioners. One mother I interviewed, Jill, is a physician who also has a Master's degree in public health. She discussed how she became *personally* aware of

vaccination issues while she was pregnant, and how her awareness as a mother was different from her understandings as a clinician and researcher:

During pregnancy you just talk -- about stuff. How you want to do stuff, where you want to birth, and what kind of prenatal care you want, and generally in my experience, pregnant ladies don't talk about after birth very much, because they are kind of focused on that whole, "Whoa, there is going to be a birth!" And after that comes some more 'hands on', how do you do it? What do you do with this baby? How do we change a diaper? But for us, um, I think part of it came to a head when we were thinking about who was going to be the baby's doctor... Starting out from the start, we needed to find someone -- I guess backing all the way up -- we wanted to have the baby at home. Once we arrived at that decision, it was kind of like, "OK... We have to find a doctor who is going to be supportive of that and who is going to go with us from there." So as we were thinking about that, we wanted to go meet some doctors and find out what they think of, what is their philosophy of childcare and all that. Since we are going to be doing that, let's talk about our philosophy. What do we want? So we started out with the birth, homebirthing, and the perinatal, peribirth medical interventions, like the vitamin K injections and like the erythromycin ointment. So, we, me being a medical practitioner and [my husband] being a very smart man, we... we started out with our base of knowledge, our fund of knowledge, which is this is what the medical establishment does. We were taking birthing classes from a non-traditional midwife, trained homebirth practitioner outside Boston [laughs], who gave these fantastic natural birthing, prenatal education classes from her home. And one of her sessions was on immunizations, vaccinations, and her take on it, so we got our information, some information from her, printed information, her opinions, her take on it, and we got information from the web, of course, because everyone goes to the web now. And we did a lot of thinking and talking about that. So before the baby came, we had pretty much decided on no vitamin K, no erythromycin ointment, um. We had interviewed a few docs for the baby, and asked them pretty much, "We are having a home birth baby, we don't want these interventions at birth, and we haven't decided what we feel about vaccinations yet because we haven't had time to do all the thinking and reading about it." And I was still working full time, so I was like, OK we'll have the baby, we know we don't want Hep B, which is the one they normally give on the first day, we know that, and we can talk about why, but we knew that from the start, and then the next ones wouldn't be due for a month or two anyway, so let's just buy some time. So that is how we started out.

Jill and Anna's interviews mentioned the importance of the internet as a source of health information. Results reported in this work indicate that parents pressured to vaccinate are relying on the internet more than non-pressured respondents, regardless of vaccination behavior. This finding should be taken into account with the findings of other researchers. Gellin et al (2000) found that parents may not be distinguishing between

credible and non-credible websites. Wolfe, Sharp, and Lipsky (2002) found that sites adverse to immunization also address a range of items reflecting mistrust of medicine. Sibbald (1999) found that most sites presenting vaccine information include unclear or false information as well. Leask, Chapman, and Hawe (2000) report that a common technique of vaccine-adverse sites is to rely on emotional messages, which Meszaros et al (1996) contend are particularly effective in influencing parents' decisions about vaccinations. Taken together, these findings may indicate a trend: as internet use becomes more pervasive, parents may be unknowingly relying on unclear or inaccurate information about vaccinations and other child health issues. And even when the websites parents visit are more credible, highly educated parents with a heightened sensitivity to vaccine concerns from other sources may find that this information buttresses their concerns. Anna, the Colorado mother from whom I quoted above, said:

I actually found the CDC rather convincing in NOT vaccinating. I don't think that was their intention! [Laughs.] But reading their literature... I also had, my midwives had extensive libraries, both of them, and I borrowed several books on vaccination. And one of them was fairly propaganda laden, to the point of saying that AIDS was an introduced, purposely designed, genetic attack, and I was like, "OK, I'm not reading this anymore." 'Cause if you are going that far over to that extreme, then I can't really trust any information you present. So I stopped reading, even though that was in support of non-vaccination. I felt like it was too propagandized, and I couldn't trust the information. I've also surfed the web quite a bit, and read a lot about immunization online. And then in the newspaper stories, I've read various things.

Streefland et al (1999) discuss how shared beliefs about medicine, disease, and public health constitute "local vaccine cultures," which help shape parents vaccination behaviors and beliefs. Parents' social interactions within networks of other parents support the beliefs and behaviors of others; this is true for vaccine accepting or rejecting behaviors. While the dominant "vaccine culture" in the US is still supportive of vaccinations, the implications of evidence from this study, buttressed by the findings of Freed et al (2004), CDC (2002), and Gellin et al (2000), suggest that the vaccine culture may be changing. Descriptive findings indicate that support for alternative decisions is an important factor in

understanding vaccination postponement and refusal decisions. Parents who are enacting vaccine decisions that counter the norm and those who feel pressure (regardless on vaccine uptake) are more likely to be in a network of other parents making alternative vaccine decisions. This is supported by data from the qualitative interviews in which every parent mentioned their experience of deriving support and sharing information with other parents who also were questioning or opposing vaccinations. What is more, these networks were not only face-to-face, as several parents interviewed referred to virtual networks via the internet.

Yet, while support from social networks may be important on its own, it is when I examined the simultaneous effects of independent variables in the conceptual model that a key support factor is revealed: perceived physician support. Support from doctors decreases the odds of pressured acceptance, a finding consistent across educational level and minority status. If parents do not perceive that their doctors are supporting them, and may in fact be pressuring them, parents accepting vaccinations under pressure may be more likely to opt out of vaccination in the future. While this cannot be assessed with these quantitative data, it is conceivable that the experience of pressure and lack of physician support may negatively influence future decisions. Evidence from qualitative interviews shows a pattern where a factor contributing to parents' revision of vaccination uptake decisions over time was the perception of lack of support or outright judgment of them by physicians. Moreover, these were largely parents who had insurance and the ability to change physicians more easily.

Given the salience of physician support, even in the presence of vaccine questions, it would seem that the current medical care delivery environment, where time is likely to be at a premium and physicians are pressed to do more, is at odds with parents getting the time they may need to address vaccine concerns, feel supported, and make fully informed decisions about vaccinations. Patient-physician encounter times for pediatric visits are

related to parents' satisfaction with the care their children receive, as are parents' feelings that they were able to get all their questions answered during the time they had with the physician (Halfon et al 2004). While quality of doctor-patient interactions and the ability of both parties to effectively communicate their concerns and perspectives to one other are also important contributors to patient satisfaction, time seems to be an essential facet of perception of support. Evidence suggests that pediatric visit times have not decreased in recent years (Ferris et al 1998), but office visits are packed with more topics that need to be covered, and vaccinations are one of these. Consider that a minimum of twenty doses of vaccine against twelve diseases are recommended between birth and 18 months. The vaccine concerned or questioning parent may be left feeling squeezed to get their questions addressed while physicians may be feeling the constriction of managed care productivity requirements. Thus, while physician support can decrease the likelihood of a parent perceiving pressure to vaccinate, resolving vaccine concerns (and increasing the parent's feeling of support) in the current time-pressed medical care environment may be more difficult than ever.

The body of evidence presented in this work suggests that parents are not making vaccination decisions in a vacuum. They are influenced by social forces in the form of social networks, doctor-patient interactions, and an information environment charged with vaccine controversies. Further, it appears that the dynamics of privilege significantly contribute to the trend of vaccine questioning and postponement or refusal. While it is not surprising that parents with a greater ability to enact social power would be successful non-vaccinators (or even pressured acceptors), it is contrary to an alternative hypothesis I offered early on in this project: specifically that socially marginalized or disempowered parents – those with less education, public insurance, lower incomes, and minority status – would comprise a significant portion of pressured acceptors. I offered contending hypotheses. The first was that parents experiencing a difficult time accessing reliable,

consistent care from health care providers they know and can develop a relationship with may not be able to have their vaccination questions answered and may consent to medical interventions about which they have lingering reservations. If pressure comes from schools and daycares, disempowered parents may not be as likely to challenge the vaccination mandates because they would have a decreased ability to seek out legal assistance to obtain exemptions and would have fewer alternatives such as home schooling or private schools. The second hypothesis was that parents running up against barriers to obtaining health care for their children may be more apt to accept physicians' recommendations without asking as many questions precisely because health care is the commodity they are seeing but otherwise lacking. Rather than rocking the boat, disempowered parents may be quite about their concerns. A third possibility is that due to constricted access to debates about immunizations, parents with fewer resources may not be questioning vaccinations.

Evidence from this research favors the latter two hypotheses. It is not parents with fewer resources who are likely to be pressured acceptors of vaccination, but parents with higher status and more power who have needling doubts. All the qualitative interviews I conducted were with non-minority parents and all were well educated. In fact, I was unable to interview any minority or lower SES parents, despite trying to make contacts through daycare centers serving lower income families. An informal discussion I had with an African American mother who was becoming aware of vaccination issues was revealing: this woman said, "We [African Americans] love medicine. We want all we can get! We aren't going to challenge it." (I was unable to contact this mother after our informal discussion despite multiple attempts to reach her.) Jill, the physician-MPH-and non-vaccinating mother whom I quoted above, spoke of her experience with immigrant and minority parents in her medical practice. When I asked her if she has encountered many patients raising vaccination concerns, Jill said:

You know, I haven't. And part of that is the nature of my clinics. My clinic is 80% immigrant, and they come in demanding shots. They come in demanding their flu shots. They come in demanding vitamin supplements. And it is, um, part of being in the 'good world,' the better world, and wanting to better for their kids – "I want my flu shots, you better give me my shots."

CM: Do you think any of that comes from the standpoint where they may have seen diseases, whereas American parents raised in the United States may not have seen the diseases?

Jill: There may be an element of that. The reason I pause and kind of doubt is because a lot of them are young moms, they are first time moms, and I don't think they've seen much. Or I don't think, I think they have seen a lot of illness, and they may, kind of in the sense of, you know, any medicine is good medicine, just give the kid some medicine, um, you know, it must be helpful. So I think they have seen a lot more illness and sickness in kids than we have. I don't necessarily think it has been the kind of sickness or illness that can be prevented by having a shot, having a vaccine, in [the town where the clinic is located] there is no wild type polio around. And, they're not going to be exposed to it. I think it is more associated with another issue that comes up with my patients is, um, formula feeding. 'It must be good.' It is part of the -- more is better, right? More is better. 'Yeah, I have my breast milk, but I can give them formula, too, because that is better, right?'

There may be parallel processes at work, each explaining a portion of why minority parents would be less resistant to vaccinations than non-minority parents. One process may be cultural variations in perceptions of risks stemming from differences in infant and child morbidity and mortality. Data from the National Center for Health Statistics show consistent racial disparities in infant and child mortality, with higher mortality rates for African American and Native American children than for Whites, Hispanics, and Asian/Pacific Islanders (Arian et al 2003). As a result, independent of education, some minority parents may be more likely than non-minority parents to view losing a child as a potential reality. As such, these parents may be more accepting of illness preventing measures, including immunization.

In conjunction with racial disparities in mortality, less socially powerful members of society are likely to meet systematic obstacles accessing stable and reliable health care, thereby hampering their ability to have their health-related questions answered and their decisions enacted. In addition, lower status parents would not have the same access to

sources of alternative vaccine information, such as websites and complimentary and alternative practitioners, as would parents with more resources, thus they may not be as tapped into vaccine controversies. Thus, the picture of parental vaccine resistance is one shot against the backdrop of the dynamics of privilege.

Why is this important? In addition to contributing to the sociological illustration of how social class and power operate in contemporary America, one reason the impact of the dynamics of privilege are important to this phenomenon is that the same people who are more likely to postpone or forego immunization may also have the resources to expose their children to increased disease contraction risk through travel. Of course, a parent's decision to postpone an immunization for a young child does not mean that child will remain unimmunized later in life. He/she could become immunized well before he/she is likely to travel. Indeed, some non-immunizing parents I interviewed expressed the sentiment that while they would prefer that their children not be immunized, they would leave the decision up to the children as they got older and could decide for themselves if they accepted the potential risks and wanted the benefits. As other parents said, once an immunization is given, it cannot be taken back, so they felt more comfortable letting their children choose for themselves. Yet, while some children will be immunized, others will not. The introduction of one case of a communicable disease in a population with a substantial number of incompletely, under-immunized, or unimmunized people could pose serious medical problems for a community. As an illustrative example mentioned earlier in this work, a CDC advisory in the summer of 2004 reported a confirmed case of an unvaccinated American two-year old child returning from a trip in Asia while in the infectious stage of the disease. Other passengers on the flight resided around the United States and elsewhere. If the trend of non-immunization continues, public health across the nation (and indeed the world) could eventually become compromised.

Risk Society and Immunization Resistance

My goal in the second part of this study was to assess how well Beck's theory of risk society applies to the phenomenon of vaccine questioning and resistance. Beck's theory posits that under the conditions of modern society, the nature of risks people face are different in type and scope than the risks confronted by people of previous epochs. First, modern risks are not necessarily risks from the natural world, but are more likely to result from human interventions into the natural world. Further, the risks we now face have consequences that could transcend time and space, affecting future generations while even possibly escaping detection in the present. At the same time, the indeterminate nature of risk means that there is a range of expert opinions about how much risk we face, and to what degree it might be experienced. This is the contested knowledge of experts: no one person or system of knowledge can specifically and clearly assess the treat posed by many modern risks, and as a result, different experts may (and do) differ in their pronouncements. As a result of these two forces (contested knowledge and the modern nature of risk), Beck contends that individuals are increasingly thrust into a process of risk assessment, necessarily making their own decisions about risk while needing to rely on the information presented to them by the very experts about whom they may be skeptical.

As I stated in the introduction to this work, my intent was not to measure whether or not we are in a risk society. That would not be possible with the cross-sectional design of the research I have conducted. Rather, I assumed from the outset that elements of risk society are operational in shaping the context in which parents make a variety of decisions for their children, including vaccine decisions. Thus, I measured parental attitudes and perceptions about components of risk society and then tested how variations in these perceptions contribute to parents behaviors around vaccinations with and without the context of pressure. (Of course, there is the possibility that Beck's contentions about the nature of risk in modern society are flawed, and perhaps the nature and scope of modern

risks are not different from those faced by people in prior eras.) Assuming this is true, however, I proceeded to examine whether there was empirical support for Beck's argument in the phenomenon of vaccine resistance and refusal. As it is specified in Figure 2.1, my conceptual plan addresses several elements of Beck's theory. Figure 5.1 replicates the conceptual plan and provides a summary of the main findings.

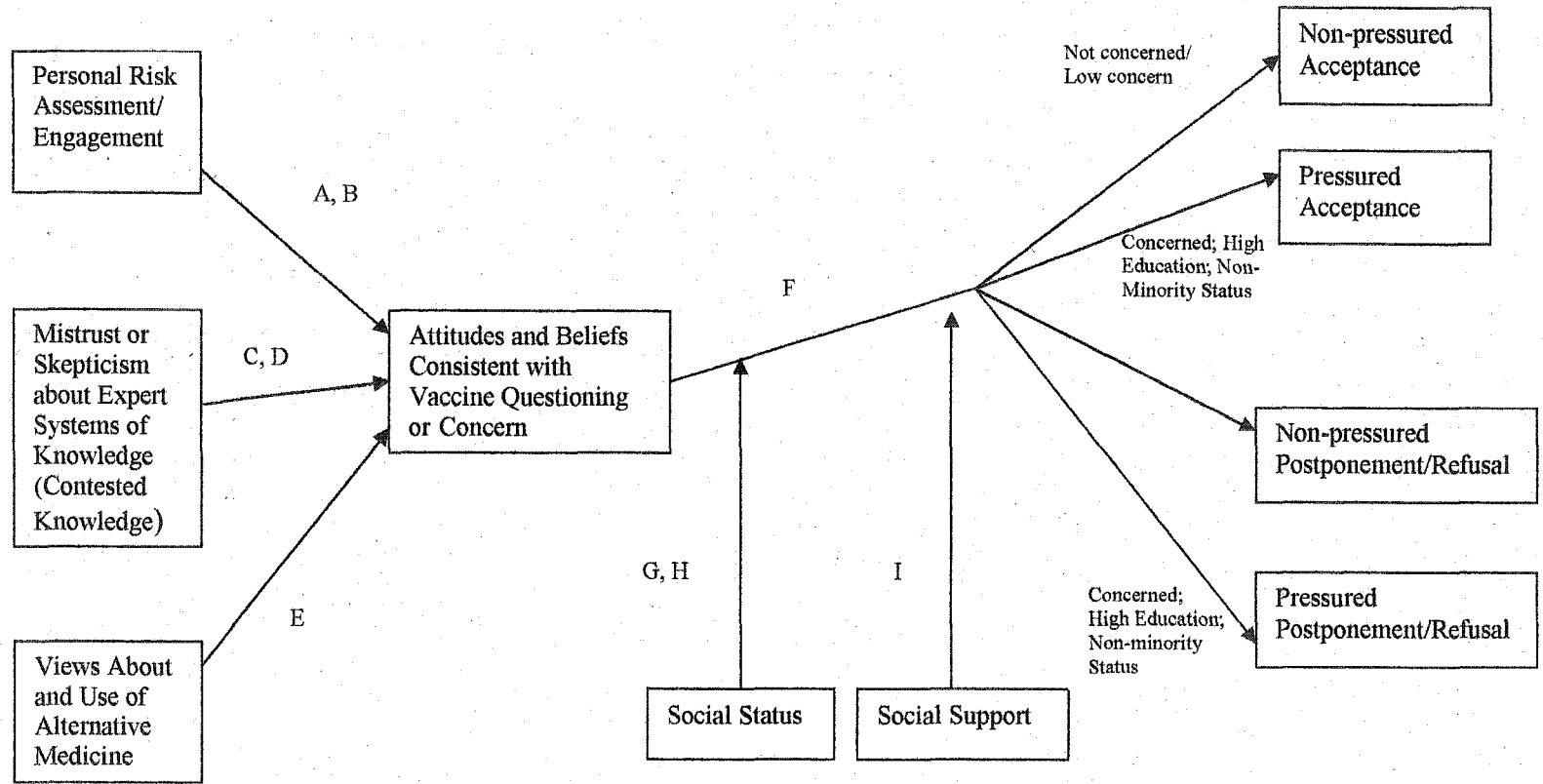


Figure 5.1 Conceptual Model and Summary of Main Findings

Summary of Main Findings as Depicted (by Letter) in Figure 5.1

- A. Health risk awareness does not have significant independent effects of decision-pressure, but there is a suppressor effect of vaccine concerns on this relationship. Health risk awareness significantly reduces the odds of pressured refusal or postponement when vaccine concerns are controlled.
- B. Health risk mastery significantly decreases the odds of non-pressured postponement/refusal and pressured acceptance relative to the norm of acceptance. The direction of these associations persists when vaccine concerns are controlled, and the associations become slightly stronger.
- C. There is an independent effect of mistrust of science and medicine on vaccine behavior, reducing the odds of pressured acceptance. This relationship is entirely mediated by vaccine concern.
- D. There is no independent effect of mistrust of government or corporations on vaccination behaviors. This is unchanged when vaccine concerns are controlled.
- E. There is no significant effect of alternative medicine on vaccination behaviors.
- F. Vaccine concerns are significantly associated with increasing the odds of pressured acceptance and pressured postponement or refusal relative to the norm.
- G. Education moderates the relationship between vaccine concerns and decision pressure. In respondents with more education, vaccine concerns increase the odds of pressured acceptance and pressured postponement/refusal, separately. In respondents with lower education, vaccine concerns increase the odds of pressured postponement/refusal to an extent far less than is found for better educated respondents.
- H. Minority status significantly moderates the relationship between vaccine concerns and decision-pressure. For non-minority respondents, vaccine concerns increase the odds of pressured postponement-refusal and pressured acceptance, separately. The magnitude of the association is stronger for non-minority respondents than for all respondents.

I. There is no evidence of a conditional relationship between vaccine concerns and decision-pressure by any support variable.

While *general* health risk awareness and health risk mastery decreased the odds of making alternative vaccination decisions, vaccine-specific concerns (which may be a type of risk awareness) do dramatically increase the odds of postponing/foregoing, or feeling pressured into accepting. Whether or not vaccines actually pose a threat to our health (as many non-immunizing parents fear) in the form of weakened immunity, enhanced vulnerability to developmental or neurological damage, or susceptibility to chronic disease later in life is not a question to be addressed here. What is presented for scrutiny, however, is the assertion that parental *perceptions* of vaccine safety, their concerns about vaccination mandates, and their subsequent vaccine uptake behaviors are in keeping with Beck's outline of risk society. Once they perceive the potential for heightened risk, vaccine questioning parents are proceeding in personal risk assessment, informed by contentious information, which reveals a schism in the authority people formerly granted to institutions such as medicine, science, and the government. That the effect of mistrust of science and medicine on decision-pressure was mediated by vaccine concern may signal that vaccine concerns incorporate parents' medical mistrust and skepticism.

Interview data reveals that parents delaying or opposing vaccines perceive a lack of scientific accord about immunizations, and they also are cognizant of the influence of pharmaceutical companies on governments and doctors. (While the association of mistrust of government and corporations was not significant in predicting vaccine behavior in the multivariate analyses, I explore this relationship via the qualitative data because it is illuminating of the processes Beck outlines.) Dorothy, a mother of one child living in Washington state, discussed how she feels doctors and parents approach the vaccination

issue with different information and how she was concerned about the influence of vaccine manufacturers in promoting and researching the safety of their own products:

I think that [doctors and patients are] coming at this with different information. I don't think that physicians would ask people to do things that they really thought were dangerous or harmful. I think they truly believe that vaccinating is the right thing for every kid, and that there is no give reason why someone would choose not to do it. I think they are very confused why someone would make that decision. Um..., so yeah, I, I, I also feel a little cynical about the role of pharmaceutical companies in the political issues that affect physician decisions. But I don't think that most physicians, consciously, think that there is anything wrong with vaccines.

CM: Could you explore the pharmaceutical political issue a little more?

Dorothy: Well, um, let's see... How can I articulate this? Um, I think they're a lot of issues, and the vaccines are just one of them. There are very few companies that actually make vaccines, and so they have a lot of power and influence over how they are made, and what is made, and distribution of them... And so, there is kind of a conflict of interest in terms of supply. And I think even some of the studies that were done on vaccine safety were funded by the same interest.

Bradley, a father of four children from Maryland, in a lengthy segment of his interview, echoed these sentiments and articulated his perception of the lack of consensus among doctors about vaccinations:

Um, basically, look, there is an issue here. We don't know what the issue is, and we have ignited a rather spirited discussion in our community about vaccines, which I think is very, very healthy. None of which has been initiated by these people's doctors and a lot of our friends are having the same experience we had, now that they are raising the issue with their doctors, their doctors are saying, "Ok, we think there is an issue too." It's like wait a minute, what are you getting at? Why [don't the parents] say, "That is what we are paying you to do!" [The doctor] should be saying, "Hey, I have an issue with vaccines..." And the approach is varied, some pediatricians are saying there is no reason to give vaccinations before the age of five, let's wait. Other pediatricians are saying, you know, "Now that you say something, I'm not very comfortable with the MMR, either. Let's do an M, a separate M, and another R. Let's divide out those and I think that is a safer way to proceed on that." The Thimerosal issue [gasps] -- who fell asleep at the switch there? It's, it's, it's beyond belief to me. You know, we've had four children, and with each of the pregnancies my wife's OB/GYN providers have said, "Do not eat fish because there is a chance that there is a trace residual amount of mercury in the fish because of pollution of certain waterways, OK, so our advice to you is just stay away from it." What idiot, I mean, it is, pardon my emotion on this issue, but how it is that the profession that is telling my wife to not eat fish because there might be traces of mercury in it, allows mercury to be put into vaccines that are injected directly into my child?

A child that is supposed to be kept safe from the --- I mean the oceans are the biggest aggregate you can imagine. Even the great lakes are a big aggregate, but now you are talking about injecting mercury directly into my child's blood stream? And it is like what the hell is going on? You know, who is the idiot who is allowing this to happen? Then you know, the extent of the ignorance on this issue, um, is just mind boggling, because we then also talked to our pediatrician about the Thimerosal issue... I was like, "On the Thimerosal, what is this, do we -- what is the situation?" They {the doctors} said, "Oh no, well, all Thimerosal has been taken off the market." False. That was not true and doctors weren't checking... The government did not take Thimerosal off the shelf, they just forced the drug manufacturers to stop adding it. They allowed them to work through their existing stocks! Which to me, is like how does that happen? How can you? You recognize there is a danger. It is like saying, OK, um, the Ford Pinto has a terrible gasoline tank problem, but there is no need to recall. We'll cycle through those accidents soon enough, and statistically the number of accidents will have gone down because we will have worked through all those bad Pintos. What the hell is going on? I've gotta say it also, our experience, generated a profound distrust of the medical community. Um, and to realize that all of their {doctor's} notepads and stuff, they are all paid for by the pharmaceutical companies. Merck. You know, on the pad, or, if I showed you {his son's medical} records, it is like one, it is like one streaming advertising campaign for all these drug companies. Everything the doctor is going to be doing is related to the drug companies.

While Dorothy and Bradley are non-immunizing parents, and their sentiments may not be representative of all parents, they do show the roles mistrust, confusion, and perceived lack of scientific accord about the risks and benefits of immunization can play in vaccine decisions. If these experiences become more common, however, and are shared by a wider range of parents, we could expect that questioning of vaccine (specifically) and medical recommendations (generally) have yet to reach their zenith.

According to Beck, class inequalities found in modern industrial societies are also part of risk societies. Class and risk are inversely related, and while everyone in a risk society faces the potential for the consequences of the risk, those with more resources may have the ability to "purchase safety and freedom from risk" (Beck 1992: 35). While they may not be able to directly purchase safety as if it were a commodity, the analogy is that parents with more resources have access to information which appears to shape their decisions. They also may have more mastery, which is related to education, providing them with a means by which they may be able to raise their concerns with physicians and

enact their decisions. More resources may also mean a parent can seek counsel to obtain a state vaccination exemption, seek out alternative or complimentary health care, home school their child, or send them to a private school as an alternative to complying with public school vaccine requirements. They would also be more able to change doctors if they did not feel support for their decisions. Beck's explanation of prevailing class inequalities in risk society appears to explain why vaccine questioning and postponing/foregoing parents are largely coming from more privileged groups. In the survey data, this was supported by the associations between education and non-minority status and vaccination postponement/refusal. In the qualitative interviews with vaccine refusing or postponing parents, all interviewees were white and all but one had a college degree.

While several of Beck's contentions find support in the qualitative data, I sought to test how well the theory explains the phenomenon in general. The conceptual model presented in Figure 5.1 finds mixed support. For instance, health risk awareness reduces the odds that a respondent would be a pressured acceptor (relative to non-pressured acceptance). This was counter to what I had hypothesized; I had postulated that in the face of vaccine questions, more mastery would increase the odds of non-pressured refusal. Beck's theory, however, does not delineate *how* individuals will decide about the risks they are willing to take, only that they will engage in individual risk assessment and management. These survey data indicate that this is what parents are doing. Perhaps awareness of risk (in the face of contested knowledge and diminished faith in experts) leads most parents to *accept* vaccination. It is possible that risks perceived in one domain could push parents into more support (or less skepticism) in another domain if the balance of risks and benefits is weighed. For instance, parents perceiving a greater threat from disease than from vaccinations may be non-pressured, normative acceptors of vaccination. The influence of parental risk mastery as a significant contributor to the decreased experience of

pressure is also supportive of the theory; parents are not only engaging in personal assessment of risk, but feel the capacity to manage risk.

The application of the theory is limited in teasing out *how* general parental awareness of health risk influences vaccination behaviors. This would require further examination in future studies. If, however, we view vaccine concerns as a facet of possible risk awareness, then we do see a clear and definite relationship between perception of vaccine risks and dramatically increased odds of perceiving pressure, whether vaccinating or not. In addition, the very perception of pressure may be revealing that parents sense the state of tension existing between realms of expert knowledge. If parents accept vaccination without perceiving pressure, this may be because their knowledge and beliefs concur with medical recommendations and/or the government policy that mandates vaccination. But parents who perceive pressure would appear to be more aware of a conflict between scientific recommendations and government policies. Thus the perception of pressure on the part of individual parents may be the social manifestation of the broader context of contested knowledge.

Limitations and Directions for Future Research

While this study reveals important patterns in the social context of parental resistance and refusal of childhood immunization, several limitations should be acknowledged. These include 1) the nature of the cross-sectional research design; 2) resources available for survey data collection; and 3) my articulation of the conceptual model.

First, the survey findings reported here are cross-sectional. While these data are well suited to providing a kind of snap shot of parents' vaccine decisions, attitudes, and beliefs at one time, they cannot provide any information about how these factors may change over time. As evidence from the Centers for Disease Control's National

Immunization Program indicates, the numbers of parents raising concerns about immunization and seeking religious or philosophical exemptions from mandates are rising (CDC 2002). Longitudinal data could address whether the same parents who are raising concerns at one point in time, but who have not postponed or refused a vaccination may be likely to become postponer/refusers in the future. Further, parents who experienced pressure to vaccinate despite their desire not to might delay or forego an immunization for a child in the future. Vaccine acceptance and pressure are not static. Longitudinal data may reveal if the interplay of pressure, concerns, support, and decision making may manifest itself differently for the same parents over time or with subsequent children.

Longitudinal data would also allow researchers to determine if there are cohort differences at work in parental attitudes and decisions about vaccinations. In a global climate that has become more sensitized to a wide array of risks in the years following the September 11, 2001 attacks, parental decision making about a host of health risks may be undergoing change. Longitudinal data could allow researchers to explore this evolution.

Finally, Beck's theory of risk is inherently premised on the idea that there has been a change over time in the risks people face. While I have assumed this in the present work, a full and complete evaluation of Beck's argument would necessarily require longitudinal data.

A second realm of limitations to this study deals with the resource constraints on my data collection. One outcome of these constraints was the small sample size of completed surveys, reducing the statistical power of the analyses to be able to detect effects and associations that may, in fact, exist in the population. While 346 parents began surveys, only 296 finished; the remaining interviews were interrupted because of time and schedule restrictions faced by the interviewees. (This is perhaps not surprising since all were parents of young children.) While telephone interviewers made every effort to set appointments to complete the interviews, budgetary and personnel restrictions meant that

not all appointments could be kept. While some parents were called at specified appointment times and were not home, others requested appointments at times when there were no interviewers available to place the call. The budget did not allow for more data collection hours, particularly during the day when there were low rates of completed surveys, and there were few trained interviewers available to work during the morning and early afternoon hours. As a result of my resource constraints, there was a relatively low response rate. There is also the possibility of participation bias where parents who took part in the survey are somehow different from parents who did not.

Budgetary constraints affecting data collection also mean that I am unable to address the dynamics of vaccine concerns and behaviors among a particular group in the population: parents who speak English as a second language or who do not speak English. These parents were not in my sampling frame, but the vaccine concerns and experiences of this group should be explored in future research. Bivariate analyses presented in Chapter 3 revealed that respondents speaking a language in the home other than English expressed more vaccine safety concerns than did English speakers. While these data do not indicate that these safety concerns have translated into vaccine refusal behaviors, this may be due to the fact ESL parents were underrepresented in this study; less than 5% of the sample spoke a language other than English in the home. Further, no non-English speakers were interviewed, yet 17% of the calls placed were answered by persons unable to understand interviewer requests to speak with an English-speaking adult. While we do know that culture, religion, and folk beliefs have an influence on people's medical decisions (Fadiman 1998; Patcher 1994), we do not know how vaccinations are perceived by non-English speaking parents in the US. Despite the practical difficulties associated with a cross-cultural, multilingual study, examining vaccine questioning and behaviors in this population deserves more attention.

Also resulting from the small sample size was my inability to conduct analyses with vaccine postponers teased out from vaccine refusers. While I have been able to make important conclusions about the phenomenon with these two groups classed as one, there may be differences between the two that should be investigated in further work. I also would like to conduct analyses with a sample large enough to investigate the effects of perceived pressure from physicians and schools/daycare centers, as the effects may be different.

The study presented here may have weaknesses attributable to my articulation of Beck's theory of risk society. This theory has been applied most often to environmental-related risks, and I assert that my application of the theory to a social-medical phenomenon is a strength. A strong social theory should outline principles that explain a wide variety of social processes; it is encouraging that Beck's theory has found some empirical support in the present work. As Levine (1995) argues, the rapid growth of medical sociology has led to a lack of creative integration of other perspectives, methods, and findings. Thus, to the extent that my work offers a creative application of a non-medical social theory to a social medical phenomenon, this work may contribute to the field. Strengths noted, however, there are weaknesses in my specification of the conceptual model and the specific measures I have used. As addressed elsewhere in this dissertation, there is likely to be reciprocal causation at work, influencing perceptions of health risks, risk mastery, mistrust and skepticism of expert knowledge systems, alternative medical orientation, and experiences of support and pressure. This limitation could be addressed by longitudinal data allowing researchers to better establish the temporal ordering of events. Furthermore, my measurement of the concepts of Beck's model may not be valid operationalizations of Beck's ideas. Before further work would proceed, I would want to re-examine survey items with an eye to bolstering construct validity.

In preparation for a larger study of parental questioning and refusal of vaccinations, I plan to revise the survey instrument to include several more items exploring additional domains. For example, I want to also assess the extent to which parents perceive risks or concerns in realms other than immunizations. Do parents express concerns about or disagreement with other medical recommendations such as circumcision, antibiotic use, and psychiatric prescriptions in pediatric populations? How fearful are parents about environmental risks and threats to health? I also want to examine how resourceful parents consider themselves in mitigating these risks. I would also query parents about their actual and perceived exposure to health risks, such as those risks that stem from occupation, geographic location, and lifestyle correlates (such as smoking, alcohol consumption, etc.). Finally, another possible domain for inclusion in an expanded survey would be parenting practices, as parents may make decisions about the risks they deem acceptable versus those they judge as acceptable for their children and this is likely to be manifest in medical decision making.

Additionally, I have a wealth of qualitative data that may contribute to our understanding of how parents engage in personal risk assessment and engagement in a context of continually contested knowledge. While a complete and systematic analysis of these data was beyond the scope of this dissertation project, my future work will undertake these analyses.

Despite the limitations of this project, a number of provocative issues have been raised about parents' perceptions of health risks, how parents perceive pressure and support, and how parents' social locations and resources help or hinder their expression of their will for their children's health care. By calling attention to these issues, this work contributes to our understandings of the social mediated and constructed nature of health in contemporary society.

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APPENDICES

APPENDIX A

Informed Consent Document for Face-to-Face Interviews

The aim of this research project is to ask parents about their experiences making decisions about the health care their children receive. One of these decisions is whether or not their children receive childhood immunizations. The researcher is interested to find out from parents how they arrive at the decision to forego or postpone childhood immunizations, the information they base these decisions on, and how much support they receive from health care practitioners. I would greatly appreciate your help in this project.

The following are the informed consent guidelines for my research project entitled "Parental Decision Making about Childhood Immunization." I am a doctoral candidate at the University of New Hampshire. My advisor for this project is Dr. Heather Turner.

All participants in this study are asked to read and consent to the following:

- I understand that the purpose of this research is to study how parents make the decision to forego or postpone vaccinations for their children, I understand that I am consenting to participate in a one to two hour face-to-face interview.
- I understand that this interview may be audiotaped. The tapes will be destroyed at the end of this research project.
- I understand that the researcher will keep the interviews confidential and will not identify me by name and or other characteristics.
- I understand that my participation is voluntary, and I can end my involvement in this project at any time.

If you have any questions about this study or your participation in it, please contact me or my advisor:

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If you have any questions about your rights as a research subject, you may contact Julie Simpson in the University of New Hampshire Office of Sponsored Research at (603) 862-2003 or julie.simpson@unh.edu to discuss them.

Name (Please Print): _____

Signature: _____

Date: _____

APPENDIX B

Informed Consent Document for Telephone Interviews

The aim of this research project is to ask parents about their experiences making decisions about the health care their children receive. One of these decisions is whether or not their children receive childhood immunizations. I am interested to find out from parents how they arrive at the decision to forego or postpone childhood immunizations, the information they base these decisions on, and how much support they receive from health care practitioners. I would greatly appreciate your help in this project.

I am a doctoral candidate at the University of New Hampshire. My advisor for this project is Dr. Heather Turner. The following are the informed consent guidelines for my research project entitled "Parental Decision Making about Childhood Immunization."

All participants in this study are asked consent to the following:

- You understand that the purpose of this research is to study how parents make the decision to forego or postpone vaccinations for their children, and you understand that you are consenting to participate in a telephone interview that will last approximately 60 to 90 minutes.
- You understand that this interview may be audiotaped. The tapes will be destroyed at the end of this research project.
- You understand that the researcher will keep the interviews confidential and will not identify you by name and or other characteristics.
- You understand that your participation is voluntary, and you can end your involvement in this project at any time.
- You may request that a copy of this consent form be sent to you for your records.

If you have any questions about this study or your participation in it, please contact me or my advisor:

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APPENDIX C

Interview Guide

The purpose of my research is to understand how parents make the decision to forego or postpone immunizations for their children. I am interested to hear from parents -- their perspectives, their decisions, their reasons. And I would like to know if they have support in their decisions from medical practitioners, their families, and friends.

I understand that this is a very sensitive topic, and I want the parents I talk with to understand that I am taking every measure to ensure their confidentiality and anonymity. The tapes of these interviews will be destroyed after they are transcribed, and parents will not be identified by name in any written documents. I will not discuss with anyone what is said by particular respondents in their interviews, and other than referrals that you may make on my behalf, I will not mention your name to anyone.

- Do you have any questions about this project?
- How many children do you have?
- How did you arrive at your vaccine decisions? (What are these decisions? Postponement/foregoing?)
- What sources of information do you rely on for your vaccine-related information? Magazines/internet/support groups/books/religion/etc?
- Have you read/seen any information in the popular press about childhood vaccinations that has influenced your decisions?
- If any of your children received any vaccinations, did they have any signs or symptoms of adverse reactions?
- Did you have support from your partner in this decision?
- Did you receive support from your child's health care practitioners? Did they encourage or discourage your decision? On what grounds?
- Have you changed doctors over this issue? Have you thought about it?
- Did you feel pressure to vaccinate your child, even after making your concerns known to the doctor/health care provider? Was your child vaccinated anyway? Did you give informed consent?
- Are there other medical recommendations that you have concerns about?
- Do your family and friends understand your decision? Are they supportive of it?
- Have you ever been pressured by others (friends/family/doctors) to change your mind about your decisions?
- How do you feel about vaccination mandates imposed by states?
- Are there other elements of how you are raising your child that people in your life have commented upon?
- Were you vaccinated as a child?
- Have you traveled outside of the US with your child or has your child traveled outside the US? Have there been any problems or extra concern about this because of the child's vaccinations?
- Are you homeschooling your child/ren?
- Diet? Wholefoods? Vegetarian?
- Breastfeeding opinions?
- Have you ever taken your child to receive treatment from a chiropractor? Naturopath? Acupuncturist?

- Activism? Informed Consent?
- SES (current and family of origin)?
- Education of interviewee (and partner, if any).

APPENDIX D

Tables of Summary Statistics from Survey Items and Composite Measures

TABLE D.1 Dependent Variable Summaries

<i>Q16</i>	“Have you ever made the decision to postpone or not allow any vaccinations for any of your children? (N = 310)	0=No: 79.03% (245) 1=Yes: 20.97% (65)
<i>Q16_1</i>	Postponed DTaP (N = 65)	0=No: 83.08% (54) 1=Yes: 16.92% (11)
<i>Q17a1</i>	Planning to give DTaP vaccination or would rather child never receive it (N = 10)	1=Give eventually: 80.00% (8) 2=Never receive: 20.00% (2)
<i>Q16_2</i>	Postponed Polio vaccination (N =65)	0=No: 95.38% (62) 1=Yes: 4.62% (3)
<i>Q17b1</i>	Planning to give polio vaccination or would rather child never receive (N = 3)	1=Give eventually: 66.67% (2) 2=Never receive: 33.33% (1)
<i>Q16_3</i>	Postponed varicella vaccination (N =65)	0=No: 69.23% (45) 1=Yes: 30.77 % (20)
<i>Q17c1</i>	Planning to give varicella vaccination or would rather child never receive (N = 20)	1=Give eventually: 60.00% (12) 2=Never receive: 35.00% (7) 3=Undecided: 5.00% (1)
<i>Q16_4</i>	Postponed MMR vaccination (N = 65)	0=No: 86.15% (56) 1=Yes: 13.85% (9)
<i>Q17d1</i>	Planning to give MMR vaccination or would rather child never receive it (N = 8)	1=Give eventually: 62.50% (5) 2=Never receive: 25.00% (2) 3=Undecided: 12.50% (1)
<i>Q16_5</i>	Postponed Hep B vaccination (N = 65)	0=No: 86.15% (56) 1=Yes: 13.85% (9)
<i>Q17e1</i>	Planning to give Hep B vaccination or would rather child never receive (N = 9)	1=Give eventually: 66.67% (6) 2=Never receive: 22.22% (2) 3=Undecided: 11.11% (1)
<i>Q16_6</i>	Postponed HIB vaccination (N=65)	0=No: 95.38% (62) 1=Yes: 4.62% (3)
<i>Q17f1</i>	Planning to give HIB vaccination or would rather child never receive (N = 3)	1=Give eventually: 33.33% (1) 2=Never receive: 66.67% (2)
<i>Q16_7</i>	Postponed pneumococcal vaccination (N = 65)	0=No: 96.92% (63) 1=Yes: 3.08% (2)
<i>Q17g1</i>	Planning to give pneumococcal	1=Give eventually:

	vaccination or would rather child never receive (N = 2)	50.00% (1) 2=Never receive: 50.00% (1)
Q16_8	Postponed flu vaccination (N = 65)	0=No: 92.31% (60) 1=Yes: 7.69% (5)
Q17h1	Planning to give flu vaccination or would rather child never receive (N = 5)	1=Give eventually: 20.00% (1) 2=Never receive: 40.00% (2) 3=Undecided: 40.00% (2)
Q16_9	Postponed other vaccination (N = 65)	0=No: 81.54% (53) 1=Yes: 18.46% (12)
Q17i1	Planning to give other vaccination or would rather child not ever receive (N = 23)	1=Give eventually: 82.61% (19) 2=Never receive: 13.04% (3) 3=Undecided: 4.35% (1)
Q16_10	Postponed vaccination, DK/not sure which (N = 65)	0=No: 81.54% (53) 1=Yes: 18.46% (12)
Q18	"Did you ever have unanswered questions about a shot but felt you needed to let your child get the shot anyway?" (N = 309)	0=No: 92.56% (286) 1=Yes: 7.44% (23)
Q19	"Did you ever feel that you would rather not vaccinate your child, but did it anyway because you felt forced or pressured by doctors?" (N = 308)	0=No: 94.48% (291) 1=Yes: 5.52% (17)
Q20	"Did you ever feel that you would rather not vaccinate your child, but did it anyway because you felt forced or pressured by school or daycare requirements?" (N = 308)	0=No: 91.56% (282) 1=Yes: 8.44% (26)
	Dichotomous variable based on responses to q18, q19, and q20.	0=No: 86.25% 1=Yes: 13.75%
	Dichotomous variable: made the decision to not vaccinate and did not face pressure versus people who made the decision not to vaccinate but did comply with pressure. (N=65)	0=vax rejector: 66.15% (43) 1=pressured acceptor: 33.85% (22)

TABLE D.2: Independent Variable Summaries

All items coded as 4-point scales with higher score indicating greater agreement: 1=strongly disagree, 2=disagree somewhat, 2.5=neutral, 3=agree somewhat, 4=strongly agree. Reverse coding indicated. Beneath variable names are factor loadings after oblique rotation.

Health-related Mastery Items (<i>riskmastery</i>)		Health Risk Awareness Items (<i>riskaware</i>)	
Q57rec .51	"The decisions I make can help my family avoid getting sick." (N=298)	Q56rec .45	"Nowadays people face more risks to their health than they did in the past." (N=296)
Q69rec	"People need to be	Q59rec	"There are so many

.50	responsible for their own health.” (N=296)	.30	risks in the world these days that people have to educate themselves to make good health care decisions.” (N=299)
Q70rec .79	“By the decisions they make, parents can limit the risks their children face.” (N=296)	Q67rec .63	“I am concerned about how, nowadays, disease can be spread around the world more easily.” (N=297)
		Q68rec .61	“I think there will be more ‘new’ diseases in the next ten years.” (N=289)
		Q72rec .49	“The world is a risky place.” (N=294)
Mistrust/skepticism of government/corporations items (<i>mistrustgovt</i>)		Mistrust/skepticism of science/medicine items (<i>mistrustsci</i>)	
Q73rec .56	“There are too many regulations on individuals’ choices and behaviors.” (N=293)	Q43rec .31	“In general, I have little confidence in doctors.” (N=302)
Q74rec .69	“I have less confidence in government than I used to.” (N=289)	Q54rec .73 reverse coded	“I have more confidence in science and medicine now than I did in the past.” (N=297)
Q75rec .34 reverse coded	“Overall, government regulations are necessary to protect public health.” (N=293)	Q55rec .59 reverse coded	“In general, I trust the findings of scientific research.” (N=299)
Q76rec .29	“Parents should have the right to make health care decisions for their children without the government interfering.” (N=293)		
Q77rec .58 reverse coded	“In general, I have faith in the government.” (N=292)		
Q78rec .44 reverse coded	“In general, I have faith in large corporations.” (N=291)		
Q79rec	“The government		

.70	makes too many deals with big businesses.” (N=290)		
Q80rec .66	“Nowadays, companies that make medications are more concerned with money over safety.” (N=291)		
Items related to vaccine safety concerns (<i>vaxsafety</i>)		Items related to vaccine requirements, regulations, or policies (<i>vaxreg</i>)	
Q47rec .42 reverse coded	“The shots given to children are safe.” (N=303)	Q44rec .44	“There are currently too many immunizations required for children.” (N=303)
Q48rec .71	“I have concerns about the long-term side effects of vaccinations.” (N=303)	Q45rec .61	“Parents should have the right to refuse immunizations for their children.” (N=303)
Q49rec .76	“I think that vaccines can harm the body’s ability to fight disease.” (N=303)	Q46rec .81	“Vaccines should not be required before children can go to school.” (N=301)
Q50rec .51	“Some required vaccines are not necessary because those diseases are no longer a problem in the United States.” (N=302)	Q60rec .47 reverse coded	“Vaccines are necessary to keep children healthy.” (N=297)
Q51rec .51	“The side effects of some immunizations are more harmful than the diseases they are supposed to prevent.” (N=299)		
Q53rec .35 reverse coded	“In general, the benefits of immunizing children outweigh the risks.” (N=300)		

Q58rec .22 reverse coded	"If there was a known harmful side effect of a vaccination, that vaccination would no longer be required." (N=298)		
Items related to alternative medicine views (<i>altmedview</i>)		Alternative medicine use (<i>altmeduse</i>)	"When your child has been sick or need a well-child check-up, have you taken your child to..."
Q65rec .60	"Chiropractors are more helpful than medical doctors for some types of ailments." (N=297)	Q71c	... a chiropractor." (N=296) Yes: 10.47% (31)
Q66rec .60	"Alternative and complimentary medicine are helpful alongside western medicine." (N=296)	Q71d	... an acupuncturist." (N=295) Yes: 1.02% (3)
		Q71e	... a naturopath." (N=292) Yes: 3.08% (9)
		Q71f	... an herbalist or herbal medicine specialist." (N=292) Yes: 6.16% (18)
		Q71g	... any other kind of health care provider?" (N=293) Yes: 10.85 (32)
Support from health care provider items (<i>supportdoc</i>)		Support from family and friends items (<i>supportff</i>)	
Q37rec .23	"I am encouraged by my child's health care provider to bring my child for regular check-ups." (N=302)	Q63rec .71	"My friends and relatives are supportive of the ways I parent my child." (N=296)
Q38rec .49	"My child's doctor does his/her best to keep me from worrying about my	Q64rec .71	"My friends and relatives support the health care decisions I make

	child's health." (N=302)		for my child." (N=295)
Q39rec .50 reverse coded	"My child's doctor hardly ever explains my child's health problems to me." (N=300)		
Q40rec .62 reverse coded	"Sometimes my child's doctor makes me feel foolish." (N=302)		
Q41rec .72	"My child's doctor is careful to check everything when he/she is examining my child." (N=301)	Network of others who have not vaccinated their children <i>(nonvaxnetwork)</i>	
Q42rec .55	"If I disagreed with my child's doctor, he/she would listen to my opinion." (N=300)	Q61rec	"I have friends or relatives who have chosen not to vaccinate their children." (N=371) Yes: 21.83% (81)
Child Health Items		Child Health Items	
Q6rec	"I have a child who was once so sick I thought he/she might die." (N=311)	Q9rec	"When there is an illness or 'bug' going around, my children usually catch it." (N=311)
Q7rec	"My children seem to resist illness very well." (N=310)	Q10rec	"My children's growth and development are similar to other children their age." (N310)
Q8rec	"My children seem to be less healthy than other children I know." (N=311)	Q11rec	"In general, my children have healthy eating habits." (N=312)

APPENDIX E

Survey Instrument

Hello, my name is _____ and I am calling from the University of New Hampshire Survey Center. This month the university is conducting a confidential study about children's health issue in this country and we'd really appreciate your help. First, are there any children 13 years of age or under living in the household?

If yes ask, Are you the parent or guardian of these children?

If "No", ask: May I please speak to the parent or guardian?

Once speaking with a parent repeat above.

Just to confirm, are you the parent or guardian of a child age 13 or under?

- 1 Yes – continue with survey
- 2 No – ask to talk to correct respondent
- 3 Person not available – make an appointment
- 4 No children available in that age group
- 99 NA/refused

If 4, Thank you very much, we are only interviewing people who have children 13 or under. Have a nice day/good night.

If 1: This survey will ask questions about your child's overall health and well-being, how parents like you make decisions about their child's health care, and parent's satisfaction with the health care their children receive. There is also a series of questions about specific parts of your child's health history, such as the immunizations, or shots, your child may have received. You will also be asked about your feelings about immunizations.

Any information you provide in this survey will be confidential, and your individual responses will be combined with those of hundreds of other parents. Your participation in this survey is completely voluntary and you may skip any questions you choose not to answer. This survey will take about 15 minutes to complete.

How many children under the age of 13 live in your household? _____

Could you please tell me the ages of your children? First what is the age of your oldest child?

What is this child's relationship to you?

- 1 Son
- 2 Daughter
- 3 Stepchild
- 4 Nephew
- 5 Niece
- 6 Grandchild
- 7 Foster child
- 8 Other (specify)
- 9 NA/ refused

(Repeat for all children)

The questions I'll ask you now are about your children's general physical health.

Do any of your children have ongoing medical problems, diseases, or disabilities?

1 Yes

2 No

98 Don't know/unsure

99 NA/refused

If yes: What are these conditions? _____

Please tell me whether you "Strongly agree", "Agree", "Disagree", or "Strongly disagree" (Neutral category is volunteered. 98 is "Don't know/unsure" 99 is "NA/refused")

	<i>S.A.</i>	<i>A</i>	<i>D</i>	<i>S.D.</i>
I have a child who was once so sick once I thought he or she might die	4	3	2	1
My children seem to resist illness very well	4	3	2	1
My children seem to be less healthy than other children I know	4	3	2	1
When there is an illness or "bug" going around, my children usually catch it	4	3	2	1
My children's growth and physical development are similar to other children of their age	4	3	2	1
In general, my children have healthy eating habits	4	3	2	1

Which statement best describes your _____ (age of first child) child's immunization status? (repeated for each child.)

1 This child has had ALL the recommended vaccinations for his/her age

2 This child has had MOST of the recommended vaccinations for his/her age

3 This child has had SOME of the recommended vaccinations for his/her age

4 This child has had NONE of the recommended vaccinations for his/her age

5 I do not know or I am not sure

99 NA/refused

Do you believe that (any) of your children has ever has a bad reaction from a vaccine?

1 Yes

Could you tell me which vaccination caused the reaction?

(Vaccination listed)

Could you tell me what the reaction was to the _____ vaccine?

2 No

99 NA/ refused

Did this reaction influence your decision to give other vaccines?

1 Yes

2 No

99 NA/refused

Have you ever had questions or concerns about the vaccinations your child's health care provider has recommended?

- 1 Yes
- 2 No

99 NA/refused

Do you feel the doctor answered these questions and addressed your concerns?

- 1 Yes
- 2 No

99 NA/refused

Have you ever made the decisions to postpone or not allow any vaccinations for any of your children?

- 1 Yes
- 2 No

98 Don't know/unsure

99 NA/refused

Could you tell me what these shots were?
(vaccinations listed)

Could you tell me your reasons for postponing or not allowing the _____ vaccine? (Repeat for each shot listed.)

(Repeat for every shot listed) Are you planning to give the _____ eventually or would you rather that your children never receive it?

- 1 Plan to give it eventually
- 2 Prefer children never receive it
- 3 Not sure at this time

99 NA/refused

Did you ever have unanswered questions about a shot, but felt you needed to let your child get the shot anyway?

- 1 Yes
- 2 No

99 NA/refused

Did you ever feel that you would rather not vaccinate your child, but did it anyway because you felt forced or pressured by doctors?

- 1 Yes
- 2 No

Did you ever feel that you would rather not vaccinate your child, but did it anyway because you felt forced or pressured by school or daycare requirements?

- 1 Yes
- 2 No

99 NA/refused

Have you ever changed your child's doctor over the issue of vaccination?

- 1 Yes
- 2 No

99 NA/refused

When you chose your child's doctor, was any part of your decision related to how he/she feels about vaccination issues?

- 1 Yes
- 2 No

99 NA/refused

Have you ever changed where your child goes to school or daycare because of school vaccination requirements?

- 1 Yes
- 2 No

99 NA/refused

We would like to know what sources of information you rely on for information about children's health, including immunizations. Please answer yes or no to each question.

Do you get any information about your children's health from television programs?

- 1 Yes
- 2 No

99 NA/refused

Do you get child health information from magazines?

- 1 Yes
- 2 No

99 NA/refused

Have you gotten child health information from books?

- 1 Yes
- 2 No

99 NA/refused

Do you get child health information from the Internet?

- 1 Yes
- 2 No

99 NA/refused

Do you get child health information from medical journals?

- 1 Yes
- 2 No

99 NA/refused

Do you ask family or friends for medical information for your child?

- 1 Yes
- 2 No

99 NA/refused

Do you get any child health information from medical doctors?

- 1 Yes
- 2 No

99 NA/refused

A Nutritionist?

- 1 Yes
- 2 No

99 NA/refused

Do you get any child health information from a chiropractor?

- 1 Yes
- 2 No

99 NA/refused

An acupuncturist?

- 1 Yes
- 2 No

99 NA/refused

A Naturopath?

- 1 Yes
- 2 No

99 NA/refused

An herbalist or herbal medicine practitioner?

- 1 Yes

2 No

99 NA/refused

What sources of child health information would you say are the most important to you?
(Listed)

Now I would like to ask you some questions about your attitudes and beliefs about vaccination. I will also ask you about your experiences with the health care your children have received. There are no right or wrong answers to these questions. Please tell me if you "strongly agree, "agree", "disagree" or strongly disagree" with each of the statements I read to you. (5=Neutral [volunteered] 98= Don't know/unsure, 99=NA/refused)

	Strongly agree	Agree	Disagree	Strongly disagree
I am encouraged by my child's health care provider to bring my child for regular check-ups4.....3.....2.....1
My child's doctor does his/her best to keep me from worrying about my child's health4.....3.....2.....1
My child's doctor hardly ever explains my child's health problems to me4.....3.....3.....1
Sometimes my child's doctor makes me feel foolish4.....3.....2.....1
My child's doctor is very careful to check everything when he/she is examining my child4.....3.....2.....1
If I disagreed with my child's doctor, he/she would listen to my opinion4.....3.....2.....1
In general, I have little confidence in doctors4.....3.....2.....1
There are currently too many immunizations required for children4.....3.....2.....1
Parents should have the right to refuse immunizations for their children4.....3.....2.....1
Vaccines should not be required before children can go to school4.....3.....2.....1
The shots given to children are safe4.....3.....2.....1
I have concerns about the long-term side effects of vaccinations4.....3.....2.....1
I think that vaccines can harm the body's ability to fight disease4.....3.....2.....1
Some required vaccines are not necessary because those diseases are no longer a problem in the United States4.....3.....2.....1
The side effects of some immunizations are more harmful than the diseases they are supposed4.....3.....2.....1

to prevent4.....3.....2.....1
You can't just rely on what doctors tell you; you have to make your own decisions4.....3.....2.....1
In general, the benefits of immunizing children outweigh the risks4.....3.....2.....1
I have more confidence in science and medicine now than I did in the past4.....3.....2.....1
In general, I trust the findings of scientific research4.....3.....2.....1
Nowadays people face more risks to their health than they did in the past4.....3.....2.....1
The decisions I make can help my family avoid getting sick4.....3.....2.....1
If there were known harmful side effects of vaccinations, that vaccination would no longer be required4.....3.....2.....1
There are so many risks in the world these days that people need to educate themselves to make good health care decisions4.....3.....2.....1
Vaccines are necessary to keep children healthy4.....3.....2.....1
I have friends or relatives who have chosen not to vaccinate their children4.....3.....2.....1
I would support the decision of a friend or relative who chose not to vaccinate their child4.....3.....2.....1
My friends and relatives are supportive of the ways I parent my child4.....3.....2.....1
My friends and relatives support the health care decision I make for my child4.....3.....2.....1
Chiropractors are more helpful than medical doctors for some types of ailments4.....3.....2.....1
Alternative and complimentary medicine are helpful alongside western medicine4.....3.....2.....1
I am concerned about how, nowadays, disease can be spread around the world more easily4.....3.....2.....1
I think there will be more "new" diseases in the next ten years4.....3.....2.....1
People need to be responsible for their own health4.....3.....2.....1
By the decisions they make, parents can limit the risks their children face4.....3.....2.....1

When your children have been sick or need a well-child check-up, have you taken your children to a:

Read each of the following

Medical doctor

1 Yes

2 No

99 NA/refused

Nurse practitioner

1 Yes

2 No

99 NA/refused

Chiropractor

1 Yes

2 No

99 NA/refused

Acupuncturist

1 Yes

2 No

99 NA/refused

Naturopath

1 Yes

2 No

99 NA/refused

Herbalist/Herbal medicine specialist

1 Yes

2 No

99 NA/refused

Any other kind of health care provider? (specify)

1 Yes

2 No

99 NA/refused

Now I would like to ask you some questions about your attitudes and beliefs about social issues. Again, there are no right or wrong answers to these questions. When I read each statement please tell me whether you "strongly agree", "agree", "disagree", or "strongly disagree." (5=Neutral [volunteered] 98= Don't know/unsure, 99=NA/refused)

	<i>Strongly agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>
The world is a risky place4.....3.....2.....1
There are too many				

government regulations on individuals' behaviors and choices4.....3.....2.....1
I have less confidence in government than I used to4.....3.....2.....1
Overall, government regulations are necessary to protect public health4.....3.....2.....1
Parents should have the right to make health care decisions for their children without the government interfering4.....3.....2.....1
In general, I have faith in the government4.....3.....2.....1
In general, I have faith in large corporations4.....3.....2.....1
The government makes too many deals with big businesses4.....3.....2.....1
Nowadays, companies that make medications are more concerned with money than safety4.....3.....2.....1

Now, a few final questions about your home and family life.

Is English the main language your family speaks at home?

- 1 Yes
- 2 No

99 NA/refused

If 2, What is the main language you speak at home?
(listed)

Within the last year, has your family received Temporary Aid to Needy Families, TANF, or food stamps?

- 1 Yes
- 2 No

99 NA/refused

Have any of your children been insured by public health coverage (for instance, Medicaid or CHIP plans) in the last year?

- 1 Yes
- 2 No

99 NA/refused

How many of the persons who currently live in your household are under 18 years of age, including babies and small children?

Including yourself, how many adults currently live in your household?

How many times has your family moved within the last year?

Which of the following best describes your work situation?

- 1 I do not work outside the home
- 2 I am currently not working, but am looking for work
- 3 In an average week, I work part time
- 4 In an average week, I work full time

98 Don't know/unsure

99 NA/refused

What is the highest level of school you have completed?

- 1 Eighth grade or less
- 2 Some high school
- 3 High school graduate (includes GED)
- 4 Technical school
- 5 Some college
- 6 College graduate
- 7 Postgraduate work

8 DK

9 NA/refused

Is there another adult in the household whose income contributes to the household?

- 1 Yes
- 2 No

99 NA/refused

Which of the following best describes the other adult in the household?

- 1 He/she does not work outside the home
- 2 He/she is not currently working, but is looking for work
- 3 He/she works part time
- 4 He/she works full time

98 DK/unsure

99 NA/refused

What is the highest grade in school, or level of education that the other adult in the household completed and got credit for?

- 1 Eighth grade or less
- 2 Some high school
- 3 High school graduate (includes GED)
- 4 Technical school
- 5 Some college
- 6 College graduate
- 7 Postgraduate work

- 8 DK
- 9 NA/refused

Are you of Hispanic or Latino origin?

- 1 Yes
- 2 No

- 8 Don't know/unsure
- 9 NA/refused

(In addition to being Hispanic) which of the following categories best describes your race:

- 1 American Indian
- 2 Asian
- 3 Black or African American
- 4 White
- 5 Multiracial
- 6 Other race (specify)

- 8 DK/unsure
- 9 NA/refused

Not counting business lines, extension phones, or cellular phones, on how many different telephone numbers can your household be reached?

How much total income did you and your family receive in 2003, not just from wages or salaries, but from all sources – that is, before taxes and other deductions were made?

- 1 Less than \$15,000
- 2 \$15,000 - \$29,999
- 3 \$30,000 - \$44,999
- 4 \$45,000 - \$59,999
- 5 \$60,000 - \$74,999
- 6 \$75,000 - \$99,999
- 7 \$100,000

- 97 Refused
- 98 DK
- 99 NA

If 97, Would your total 2003 household income be below \$30,000 or more?

- 1 Below \$30,000 Thank and terminate
- 2 \$30,000 or more

99 Refused Thank and terminate

If 2, Would your total 2003 household income be below \$60,000 or more?

- 1 Below \$60,000
- 2 \$60,000 or more

99 Refused

That's all the questions I have. Thank you again for your help. If you have questions about this study, please call the study director at Catherine Moran (603) 862-1876.

APPENDIX F

Inter-item Correlations

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. riskaware	1.0000										
2. riskmastery	0.3327	1.0000									
	0.0000										
3. mistrustsci	-0.1250	-0.1760	1.0000								
	0.0527	0.0061									
4. mistrustgovt	0.2398	-0.1662	0.3535	1.0000							
	0.0002	0.0098	0.0000								
5. altmeduse	0.1318	-0.0617	0.1713	0.1699	1.0000						
	0.0286	0.3071	0.0066	0.0071							
6. altmedview	0.0698	0.0104	0.1672	0.1588	0.2897	1.0000					
	0.2866	0.8741	0.0132	0.0187	0.0000						
7. vaxquest	0.0252	-0.1590	0.5541	0.3596	0.2937	0.2256	1.0000				
	0.6963	0.0131	0.0000	0.0000	0.0000	0.0008					
8. education	-0.0780	0.1072	0.0118	-0.1829	0.0525	-0.0593	0.0888	1.0000			
	0.1989	0.0771	0.8535	0.0038	0.3723	0.3606	0.1651				
9. minority	0.1104	0.0039	-0.1137	0.1871	-0.0028	0.0106	-0.0654	-0.2539	1.0000		
	0.0670	0.9479	0.0726	0.0030	0.9577	0.8683	0.3000	0.0000			
10. evernever	0.0256	-0.0704	0.1248	0.0960	0.0657	0.0506	0.2942	0.1199	-0.1049	1.0000	
	0.6722	0.2439	0.0488	0.1300	0.2489	0.4305	0.0000	0.0410	0.0652		
11. evernever-s	-0.0548	0.0105	-0.0338	-0.0258	-0.0080	-0.0495	-0.0934	-0.0936	0.1000	-0.8957	1.0000
	0.3641	0.8619	0.5950	0.6851	0.8886	0.4409	0.1383	0.1109	0.0787	-0.0000	

APPENDIX G

Institutional Review Board Approval

The two following pages present the approval letters for the research protocols for the work presented in this dissertation. The protocol for the in-depth qualitative interviews was approved July 1, 2002. The survey protocol was approved February 27, 2004.

UNIVERSITY OF NEW HAMPSHIRE

Office of Sponsored Research
Service Building
51 College Road
Durham, New Hampshire 03824-3585
(603) 862-3564 FAX

LAST NAME	Moran	FIRST NAME	Catherine
DEPT	Sociology - Horton SSC	APP'L DATE	6/28/2002
OFF-CAMPUS ADDRESS (if applicable)	[REDACTED]	IRB #	2770
		REVIEW LEVEL	EXE
		DATE OF NOTICE	7/1/2002

PROJECT TITLE *Parental Decision Making about Childhood Immunizations*

The Institutional Review Board (IRB) for the Protection of Human Subjects in Research has reviewed and approved the protocol for your study as Exempt as described in Federal Regulations 45 CFR 46, Subsection 101 (b), category 2.

Approval is granted to conduct your study as described in your protocol. **Prior to implementing any changes in your protocol, you must submit them to the IRB for review and gain written, unconditional approval. If you experience any unusual or unanticipated results with regard to the participation of human subjects, report such events to this office within one working day of occurrence.** Upon completion of your study, please complete the enclosed pink Exempt Study Final Report form and return it to this office along with a report of your findings.

The protection of human subjects in your study is an ongoing process for which you hold primary responsibility. In receiving IRB approval for your protocol, you agree to conduct the study in accordance with the ethical principles and guidelines for the protection of human subjects in research, as described in the following three reports: Belmont Report; Title 45, Code of Federal Regulations, Part 46; and UNH's Multiple Project Assurance of Compliance. The full text of these documents is available on the Office of Sponsored Research (OSR) website at http://www.unh.edu/osr/compliance/Regulatory_Compliance.html and by request from OSR.

If you have questions or concerns about your study or this approval, please feel free to contact me at 862-2003. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,


Julie F. Simpson
Regulatory Compliance Manager

cc: File
Heather Turner, Sociology



UNIVERSITY of NEW HAMPSHIRE

February 27, 2004

Moran, Catherine
Sociology
Horton Social Science Center

IRB #: 3142
Study: Child Immunization Survey
Approval Date: 02/27/2004

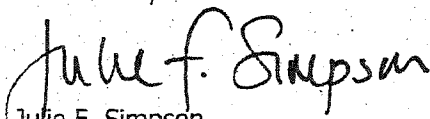
The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Exempt as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 101(b). Approval is granted to conduct your study as described in your protocol.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. (This document is also available at <http://www.unh.edu/osr/compliance/IRB.html>.) Please read this document carefully before commencing your work involving human subjects.

Upon completion of your study, please complete the enclosed pink Exempt Study Final Report form and return it to this office along with a report of your findings.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,


Julie F. Simpson
Manager

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Heather Turner

Research Conduct and Compliance Services, Office of Sponsored Research, Service Building,
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