

‘Evan is my Science’: Autism, Vaccines and Postmodern Medicine

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THESIS

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SUMMARY

This project situates the Autism-Vaccine Controversy within the larger theoretical context of postmodern medicine. The texts of two prominent figures from within the Autism-Vaccine Controversy were rhetorically analyzed using Kenneth Burke's method of cluster criticism. The benefits of this approach are two-fold. First, the Autism-Vaccine Controversy is approached holistically rather than in piecemeal fashion (as is seen in the scholarly literature on the subject) and second, the hitherto abstract theory of postmodern medicine is enriched and concretized through the exploration of a specific, illustrative case study. The overarching aim is to generate new insights into both the Autism-Vaccine Controversy and the theory of postmodern medicine.

The project draws several main conclusions. First, the feeling of voice marginalization is common to both patients and physicians, but for differing reasons and in differing contexts. Second, there is a dissonance in views between patients and physicians regarding who should be able to participate in the production of medically-oriented knowledge, and where to locate responsibility for the securing of public health. Lastly, the commercialization has intensified a bi-directional lack of trust between patients and physicians.

1. INTRODUCTION

True to its own tenets, postmodern theory comprises a multiplicity of perspectives that conflict with one another nearly as often as they concur. However, there is broad agreement among postmodern theorists that the once stable values of modern Western society are losing their familiar, fixed shape, (Lyotard, 1979) challenged by the creeping instabilities of paradox, relativism, pluralism, the unknowable, globalization and so on. While some are apt to resist this new set of values, preferring instead the comforts of tradition, the postmodern is not escapable; it leaves no rock unturned. As Morris (1998) puts it,

“Even its critics, even televangelists or conservative commentators impassioned in their defense of traditional virtues, stand within the stream they oppose, taking calls on their cell phones, eating in franchised restaurants owned by multinational corporations, raising kids who speak computerese. We are all, like it or not, postmodern.” (p. 7).

Despite the inescapable reach of the postmodern, some professions have obvious reasons to wage resistance against the instabilities that characterize the postmodern world. One such profession is medicine, a decidedly modern endeavor that has long prided itself on the irrefutability of its truth, the trajectory of its progress, and its ability to turn the unknown human body into the known—all of which have helped to position medicine atop the modern hierarchy of dominant professions. Many influential accounts of the professional dominance of modern medicine exist (Foucault, 1963; Freidson, 1970). However, to date, there have been relatively few inquiries into the challenges that

postmodernity poses for modern medicine, a profession that is struggling keep a hold on the unquestioned authority and irreproachable truth it formerly enjoyed.

While there is no simple working definition of a 'postmodern medicine,' two influential theorists, Arthur Frank and David Morris, are in agreement that, fundamentally, postmodern medicine is marked by a patient populace that has begun to understand that there are more elements involved in human experiences of health and illness than the medical story alone can tell (Frank, 1995). As the literature on postmodern medicine is thus far sparse, both authors make the case for expanded inquiry into the intersection and interaction between postmodernity and medicine. This project seeks to enrich the hitherto underdeveloped theory of postmodern medicine by exploring a specific, illustrative case: the autism-vaccine controversy (AVC).

Though opposition to compulsory vaccination has existed since the introduction of the first smallpox vaccine, the current vaccination controversy, AVC, is unique. According to most accounts, the controversy began in 1998, following the publication of Andrew Wakefield's notorious study that raised the possibility of a correlation between the Measles, Mumps and Rubella (MMR) vaccine and autism (though historical accounts like Baker's (2008) argue that the groundwork necessary for such a controversy to occur was laid prior to the Wakefield publication.) Though the study was later retracted from the journal in which it was published, and Wakefield struck off the UK medical registry on the basis of his compromised ethics and unsound science, the damage is considered done: MMR vaccination rates in the U.K. have dropped from 92 percent to 73 percent following Wakefield's publication (Stobbe, 2007) and more U.S. measles cases have

been reported in the first half of 2011 than any full year since 1996 (“Measles - United States, January -- May 20, 2011”, 2011).

The majority of AVC literature reviewed for this project is specialized, in that a single particular component of the controversy is isolated for in-depth analysis (e.g. the design of antivaccination websites, the role of expert sources in mass media coverage, the activities of parent advocacy groups, etc.) This project will argue that the AVC can be understood holistically through the lens of postmodern medicine. In doing so, insight can be gained into both the nature of the AVC itself, and also the nascent field of postmodern medicine (and its quandaries). To do so, a rhetorical analysis of highly visible yet hitherto unexamined rhetors and artifacts from the AVC will be undertaken. These artifacts consist of four books—two written by vaccine skeptic Jenny McCarthy and two books written by vaccine expert Dr. Paul Offit. It is hoped that this project will serve not only as a theoretical contribution to AVC research and the field of postmodern medicine, but also as a practical contribution to scholars of health and medicine interested in exploring persuasive strategies that are likely to be un/successful for encouraging higher vaccination uptake among a patient populace that is increasingly interested in and capable of resisting the persuasive appeals of modern medicine. In a world where global travel has become commonplace, the stakes are clear.

2. LITERATURE REVIEW

2.1 The Birth of Postmodern Medicine

Scholars, including social scientists, rhetoricians and historians, have long had interest in the unique persuasiveness with which medicine conducts its business in Western society. This interest arguably peaked in the 1970s following Michel Foucault's *The Birth of the Clinic*. With a broad focus on medical paternalism and disciplinarianism, scholars have described how the medical gaze (Foucault, 1963) structures a highly asymmetrical power relationship between patients¹ and their medical practitioners, a relationship in which 'patient agency' nearly becomes an oxymoron. Whether such a period of intense medical dominance ever truly existed outside of the scholarly literature is debatable (Coburn, 2006) but there is general agreement that the field of medicine is experiencing a period of significant transformation and unprecedented challenges to its authority. This period of flux been referred to as evidence of a transition from modern to postmodern medicine (Frank, 1995; Morris, 1998).

Shortly after the surge of scholarly interest in the medical profession, accounts of the postmodern began proliferating. Theorists Jean-François Lyotard, Fredric Jameson and Jean Baudrillard have offered some of the most influential accounts, though with divergent emphases: Lyotard focuses mainly on scientific knowledge, Jameson on structures of capitalism, and Baudrillard on modes of mediation, broadly speaking. Despite divergent emphases, there is unanimous agreement among postmodern theorists that the world has undergone and continues to undergo dramatic and irrevocable change.

¹ As is consistent with the scholarly literature, the term 'patient' here refers, overarchingly, to any individual who has received or is receiving health-related services, caring for an individual who has received or is receiving health-related services, or who has sought or is seeking health-related information for herself or on behalf of someone else. Under this usage, 'patient' is a term that will apply to everyone at some point(s) in her life.

This transformed world raises vexing questions about the natures of truth, rationality and authenticity (Webster, 1995).

Scholars continue to explore both postmodern theory and the social components of medicine with zeal, though separately; there have been relatively few inquiries into the intersections of medicine and postmodernism. In exploring the sparse literature that comprises the nascent field of postmodern medicine, three closely interrelated themes emerge: the weakening of the biomedical narrative, the proliferation of technology (communicative and biotechnology) and the recalibration of patient-physician relationships.

2.1.1 The Weakening of the Biomedical Narrative

It is argued that modernity was ushered in by, or at the very least is embodied by the Enlightenment and its emphasis on philosophical and scientific rationalism. (Giddens, 1987.) Writing in *The Postmodern Condition*, (1979) Jean-François Lyotard identifies the Enlightenment as one of the ‘grand narratives’ of modernity, the collapse of which helps characterize postmodernity. Sometimes referred to as ‘master narrative’ or ‘metanarrative,’ the grand narrative of modern times offers a totalizing explanation for why the world exists as it does, and a totalizing prescription for how the world ought to exist. The grand narrative of the Enlightenment holds an unflinching belief in science, rationality and the unstoppable progress of the two (Roberts, 2002). Through mastering the mysteries of the universe, turning the unknown into the known, the Enlightenment narrative locates science as the tool for freeing society from ignorance, superstition and other ills (Best & Kellner, 1991).

Lyotard writes that the postmodern condition can be reductively thought of as an “incredulity toward metanarratives.” (p. xxiv). With the dissolution of the Enlightenment grand narrative, ‘science’ broadly speaking, has lost its familiar shape. He goes on to explain that, “The narrative function is losing its functors, its great hero, its great dangers, its great voyages, its great goal.” (p. xxiv). In this vein, Morris states that,

“The modernist narrative of biomedicine, with its heroic doctors and researchers struggling to find a cure in time to stop the epidemic and rescue the patient or save the world, has begun to give way to a far more complicated and confusing narrative that contains painful moments of breakdown and failure.” (p. 278).

The postmodern collapse of the grand narrative form and function has left in its wake a set of values with which modern science has an unfriendly relationship: uncertainty, relativism, paradox, the lack of universal truths, etc. (Sim, 2002). These values challenge the persuasive function of authority and legitimacy within all fields of science, but these challenges are especially pronounced within the field of medicine, where persuasion is the foundation necessary to serve a patient populace: a patient must be persuaded that a course of antibiotics is necessary for improving her condition, that the benefits of x-ray radiation outweigh the harm, that cessation of smoking will ultimately increase quality of life.

The endeavor of medicine has a decidedly modern morale, rooted firmly in the belief there are objective truths about the body; the goal is to discover and apply these truths (Hodgkin, 1996). This singular truth that underlies all of medicine is referred to as the ‘biomedical grand narrative.’ Morris (1998) explains that the biomedical grand narrative is ‘a theory that reduces every illness to biological mechanism of cause and

effect.’ (p. 11). The biomedical model conceives of the body in mechanistic terms, wherein every malfunction can be traced back to biology, and treated by science, technology and their experts (Frank, 1995; Harter, Japp & Beck, 2005; Morris, 1998). Much like taking a car in for repairs, the bodily components are observed for problems; the problems are interpreted; the interpretations yield a final “diagnosis” or “story” that is relayed in a highly technical and specialized language unfamiliar and mostly incomprehensible to the car owner. As Frank (1995) puts it,

“As patients, folks accumulate entries on medical charts which in most instances they are neither able nor allowed to read; the chart becomes the official story of illness.”(p. 5).

The problem is that the expertly authored ‘official’ story of illness that Frank mentions above drains health and illness of any cultural and social context. Morris (1998) argues that,

“An awareness of the role that culture plays in the experience of illness unavoidably invokes questions and texts lying far outside the ordinary range of medical knowledge. We must explore, for example, not only laboratory data and epidemiological research, but also novels, television programs, films, advertising, bodybuilders and obscenity laws.” (p. 43).

The biomedical narrative obscures not only the cultural and social variables of illness, but also fails to acknowledge the multitude of ‘mininarratives’ that exist for every ‘official’ medical narrative of illness. These mininarratives belong to patients, the families who fret over them, the bosses who grant them time off from work, the insurance companies that decide to either accept or deny their medical claims, etc. In postmodern medicine, these

mininarratives need not necessarily be subjugated to the biomedical narrative. Frank (1995) explains that,

“What is distinct in postmodern times is people feeling a need for a voice they can recognize as their own... The postmodern divide is crossed when people’s own stories are no longer told as secondary, but have their own primary importance.” (p. 7).

In short, scholars argue that the stabilities of the biomedical model and its mechanistic paradigm have given way to the instabilities of a patient populace increasingly aware of the inextricable links between medicine and culture. This postmodern patient populace is, more than ever, interested in and capable of resisting the biomedical grand narrative and instead relying on their own individual narratives to make sense of their experiences. Though not supplanted completely, the official biomedical narrative of modern medicine has been weakened by the distinctly postmodern proliferation of patient narratives that challenge or resist the official biomedical story, and assert the unique and ungeneralizeable nature of individual experiences of health and illness. When health care professionals are not available to listen to these narratives (as is increasingly the case, given high patient volume and growing time constraints) postmodern patients find other audiences.

2.1.2 The Proliferation of (Bio)Technology

For many theorists of the postmodern, Lyotard in particular, the sprawl of technology is one of the major markers of postmodern times. Whether the expanse of technology ushered in postmodern times or is a mere characteristic of it is arguably an open question. The medical profession has always been driven by technological advances. As such, the

role technology plays in molding postmodern medicine cannot be overstated. This role is two-fold, comprised of biotechnologies that increasingly rely on patients to self-administer and self-monitor; and communication technologies (i.e. the Internet) that allow patients to seek and share health-related information.

Newer forms of biotechnology problematize the biomedical model of medicine, and disrupt the biomedical paradigm in a number of ways (Sim, 2002). One of the most noted accomplishments of modern medicine is that it has transformed numerous acute conditions into chronic conditions. With the surge of chronic conditions comes a growing reliance on patients to self-monitor their conditions and self-administer their medications. Martins (2005) chronicles the innovations in diabetes management as a particularly illustrative example: prior to the discovery of insulin in 1922, diabetes meant sure death. Now it means a lifetime of careful management lead by the patient herself. Martins explains that,

“The resulting emphasis on what an individual could and should do in the management of a disease raises thorny issues of authority...as more biomedical technologies are required to make and implement decisions, the relationship between the human body and the technologies enabling prolonged life became more complicated, offering a new view of the body as having less stable boundaries and a greater capacity for incorporating “foreign bodies” within its affected and corporeal borders.” (p. 60).

As the above quote implies, biotechnologies not only complicate issues of medical authority, but they have also begun to undermine the very objectives that the biomedical model of medicine was established to carry out: returning ‘malfunctioning’ bodies to

their standard operating conditions. With biotechnology flourishing, the medical objective is often not to return the body to its previous mode of function, but to diverge from it in an endless number of ways: wombs are implanted with multiple embryos at once, pacemakers placed within chests, lab-grown bladders serve as transplants. As Shildrick (1997) tells us,

“In the late twentieth century, the rapid development of an array of high-tech medical interventions, particularly in the area of procreation, has brought into crisis the purpose of health care. The possibilities are no longer simply those of corporeal normalization, but, on the contrary, of the transgressive interchangeability of body parts; the blurring of distinctions between life and death; the bypassing of generations in reproduction; the creation of genetically transformed individuals; and much else besides.” (p. 215).

For some, Foucaultians and feminists in particular, biotechnology is potentially liberating for patients, enabling them to regain some degree of power back from the perceived patriarchy of biomedicine. In this vein, new reproductive technologies are often singled out as especially empowering, as women have arguably been most subjugated by the biomedical, mechanistic model of medicine and the passivity it demands of its patients (Sim, 2002). However, for others, biotechnology is just a higher-tech version of medical patriarchy and dominance—called ‘technopatriarchy’ by Mies (1987). According to Mies, reproductive biotechnologies like in vitro fertilization persuade women (who have been socially conditioned to desire children) to have their bodies subjugated to science once again, albeit in a different yet equally exploitative form, by ‘fame-and money-greedy biotechnicians.’

It is not only biotechnology that bears influence in the development of postmodern medicine. Communicative technologies, specifically the Internet, are changing the way that medicine ‘does business’ and the ways patients seek to maintain health and manage illness. Lyotard prophetically wrote in 1979 that the type of information available to information-seekers in the future would have to meet the technological requirements of the people doing the transmitting, searching and researching of information. He was referring primarily to computers. In fact, for many postmodern theorists and technological determinists, the cybernetics metaphor has come to represent all of postmodern society, a society that has been subjugated to its systems of computerization (Best & Kellner, 1991).

The nature of knowledge and information has changed: in order to be useful, information must be transmittable through the technology that people most want to use. Health communication scholars point out that for health-information producers and seekers, that desirable technology is often the Internet. As access to the Internet rapidly increases across nearly all populations (Rains, 2008) so does web-based searching for health-related information. According to a 2011 Pew survey, 80 percent of Americans use the Internet in pursuit of health-related information; it is the third most popular Internet activity. In fact, health-information seeking is a more popular online endeavor than reading the news or shopping (Pew Internet and American Life Project, 2011). Communication scholars identify several possible reasons for the popularity of health searches: more patients are managing acute syndromes; patients are aware of physicians’ time constraints and view the constraints as an impediment to receiving thorough information from their physicians; patients are interested in receiving information that is

less technical than what their physicians give and are more interested in learning ‘everyday’ ways to attain healthfulness² (Kivits, 2006).

What many of the measurement studies of health-information seeking often fail to attend to is that 1) information is not a stable entity; it takes on a different shape when filtered through the web as opposed to physicians and 2) patients are not merely seeking health-information on the web; they are sharing as well, in the form of blogs, comments, forums, etc. According to Segal (2009) ‘Internet health’ is too often conceived of as a uni-directional process, wherein the web shapes the users via informing them and influencing behaviors, when in actuality the user shapes the web, too. She says,

“The user may not act back on the web purposefully, although she may do so, for example by posting something to a discussion board that then becomes part of what the next user finds.” (p. 360).

Segal’s point underscores what Lytoard (1979) argued decades ago: that the relationship between users and producers of information is less clear in a postmodern era, and the nature of the information transmitted is altered concomitantly with the change in transmission mode. Much of the literature on web health regards this altered relationship as potentially empowering for patients, who no longer have to rely on physicians for information and can ‘circumvent physicians’ attention in accordance with their own (often Web-tutored) felt experience.’ (Segal, p. 357). However, Segal finds that a number of factors problematize the concept of the web-empowered patient. The first is that ‘being informed’ is too often conflated with ‘being empowered’ regarding issues of

² In a sense, this could be described as an interest in preventative medicine—something the biomedical model does not specialize in.

health. The logic is that more information results in more empowerment. Segal argues against this notion, stating,

“...the democratization of health information, however, can include a faulty view of knowledge and expertise: the problem is not just that laypeople do not know what doctors know; it is that they *cannot* (original italics) know it. (p. 354)

She argues that not only might the patient lack appropriate medical experience with which to interpret health-related information, the patient seeking health-related information on the web may not be in the best psychological state to interpret it. The web-patient is often seeking health information while in solitude and potentially concerned about her health or the health of someone else. This provides optimal conditions for anxiety to thrive.³ White and Horvitz (2008) identify the anxiety associated with web health searches as ‘cyberchondria.’⁴ They define the phenomenon as “an unfounded escalation of concerns about common symptomatology, based on the review of research results and literature on the web.” (p.1).

While accounts of the postmodern may often conflict, nearly all will point to the tendency toward new technologies as a defining characteristic of the postmodern world, a tendency especially true of postmodern medicine. Both biotechnologies and communicative technologies have a profound impact on medicine, and continue to play a formative role in molding a postmodern medicine. These technologies provide hitherto unthinkable possibilities for managing health and illness, such as a human heart grown in a lab (a breakthrough announced in early 2011) and patients’ unprecedented access to

³ For Jameson (1991) a heightened and generalized cultural anxiety helps describe postmodern society.

⁴ ‘Cybercondriac’ was a prominent enough term to be named a Word of the Year in Webster’s New World Dictionary in 2008.

health-related information through medical reference websites like eMedicine and WebMD.

2.1.3 From ‘Patient-Physician’ to ‘Client-Provider’ Relationships

‘Patient non/compliance’ has been a focal point in both medical and social science literature, and is a perfectly representative vestige of the biomedical model in medicine. In its heyday, Rodin & Janis (1982) identified ‘patient noncompliance’ as ‘one of the most serious problems in health care today.’ It is no surprise then that as the biomedical model of medicine has begun a fundamental shift, so too has the concept of patient noncompliance. In the literature, ‘noncompliance’ most often refers to patients’ failure to follow the medication regimes advised by their physicians. However, noncompliance can refer to a wide range of patient behaviors: failing to follow a recommended diet, keep an appointment, quit smoking or follow the recommended vaccine schedule.

The term was first used by sociologist Milton Davis (Davis & Eichhorn, 1963) and became mainstream in the 1970s when the medical profession became interested in conducting measurement studies of patient compliance and the effectiveness of compliance gaining strategies. (Segal, 2005). The proliferation of compliance studies occurred at a time when sociological interest in the dominance and paternalism of the medical profession was at its peak. Elliot Freidson (1970) identified the medical profession as the ‘preeminent form of expert authority.’ Whether such a period of intense medical domination ever truly existed is debated, and over time scholars’ keen interest in the concept medical domination has somewhat abated (Coburn, 2006).

Despite the ‘preeminent form of expert authority’ held by medical practitioners, studies of patient noncompliance tend to conclude that overwhelming numbers of patients

fail to take their ‘doctor’s orders’ seriously. Clearly the medical community has good reason to pursue the issue: it is estimated that medication noncompliance alone amasses costs of nearly 100 billion dollars per year (Wertheimer & Santella, 2003). Likewise, Jackson and Huffman (1990) estimated that nearly 125,000 patient deaths occur as a result of noncompliance.

In the years since the introduction of the compliance framework in medicine, medical and social scholars alike have criticized the compliance framework for its excessive paternalism and the intrinsically asymmetrical power relationship it structures between patients and physicians. As bioethicist Holm (1993) puts it,

“The intrinsic judgment in the label “non-compliant” makes it... totally unsuitable for use in present-day medicine. If patients are to be involved as equal (or maybe even senior) partners in decisions concerning *their* health care, then doctors will have to adjust their role from being the sole decision-makers to being the expert advisers.” (p. 109).

The medical community has taken note of such criticism of the compliance model and recent efforts to introduce a model of patient “concordance,” “adherence” and sometimes even “cooperation” can be seen throughout medical and social science literature. The new ‘concordance’ model is an attempt to recalibrate the asymmetrical patient-physician relationship, and encourage physicians to think about their patients as individuals with agency and rationality. Cuthbertson & Noble (1997) go so far as to state in the *British Medical Journal*,

“Doctors and patients are equals. It is not for patients to submit to doctors. Rather doctors have their health beliefs, and patients have theirs. They are all equally valid.”

While the rhetoric of equality invoked in the above quotes may be appealing to some, Segal (2005) points out that the new concordance model does not, in fact, do away with the problem of noncomplying patients and may actually worsen it. She regards the concordance model as an impediment to patient trust in physicians and an obscuring of the nature of physician expertise. To Segal, the rhetoric of the concordance model amounts to “consumerist rhetoric and is a rhetoric of rights that may be totally inappropriate to questions of health and illness.” (p. 143). She goes on to summarize the tone of consumerist rhetoric in the current context of health care:

“American health-care “providers” within HMOs are “managed care vendors” and provider publications compare managed-care firms to “manufacturing companies.” (Freeman). American journals of “health-care marketing” report that “urgency-centers” and “surgicenters” are creating a condition of “acute competition” in the medical marketplace” where the contexts of the “medical market basket” have expanded to require rethinking of a “product line” (France and Grover; Goldsmith).” (p. 125).

The view of patients as consumers inherent within the new concordance model, however ineffective to solving the problem of noncompliance, is unsurprising given the current economic context of medical care in the United States. The U.S. spends more money per person on health care than any other country in the world, and current estimates apportion health care as 16 percent of the Gross Domestic Product (“World Health Statistics”,

2009). Additionally, since the establishment of Direct-to-Consumer-Advertising laws in 1997, pharmaceutical companies now spend nearly as much money advertising prescription drugs to consumers as they spend advertising to physicians. (“Marketing and Direct-to-Consumer Advertising (DTCA) of Pharmaceuticals”, 2010). As analyses like Segal’s suggest, this reconceptualization of patients as ‘clients’ and physicians as ‘providers’ confounds notions of medical expertise. It may also constrain physicians in their quest to best care for their patients, as they are increasingly pressured to adhere to the market-driven axiom of ‘the customer is always right.’

2.2 The Autism ‘Epidemic’ as Prelude to Controversy

Derived from the Greek word for self, ‘autos,’ the term ‘autism’ was first applied to a patient by Leo Kanner, considered the founder of child psychiatry. In 1938, Kanner began observing a set of eleven children with peculiar behavioral characteristics. In his seminal 1943 paper “Autistic Disturbances of Affective Contact” Kanner explained that these children exhibited an ‘inability to relate themselves in ordinary ways to people and situations from the beginning of life’ and possessed ‘an extreme autistic aloneness that whenever possible disregards, ignores and shuts out anything that comes to the child from the outside.’

Since its introduction to the scientific community and public, theories about the etiology of autism have abounded. Initially it was thought that autism might be a psychological reaction to a cold and emotionally distant ‘refrigerator mother.’ This Freudian hypothesis, first proffered by psychoanalyst Bruno Bettelheim (1967), was derived from researchers’ findings that autistic children were often the offspring of wealthy parents, including a college-educated mother. Though the refrigerator mother

hypothesis has since been thoroughly rejected, conflicting understandings of the etiology of autism continue.

Diagnostic rates of autism spectrum disorders (ASDs) have climbed exponentially since Tanner's 1943 research, particularly in recent decades. At present, the CDC estimates that autism rates are 1 in 110 children ("Autism spectrum disorders," 2011). The interpretation of this data is a point of contention. As Morris (1998) reminds us, postmodern illnesses often involve a degree of ambiguity (in the medical community, public, or both) about whether a given condition actually exists or results from processes of 'medicalization.' These conditions, almost always chronic as opposed to acute, are typically referred to as 'contested illnesses' and include a range of conditions that continue to be de/legitimated: Chronic Fatigue Syndrome, Fibromyalgia, Premenstrual Dysphoric Disorder, etc.

Current medical and public discourses about ASD rates involve a similar type of ambiguity. While there is broad consensus within U.S. society that autism spectrum disorders do in fact exist, the ambiguity revolves around whether or not current rates of ASDs diagnoses represent an 'epidemic.' While it may not seem like an overly consequential distinction, medical historian Jeffrey Baker (2008) tells us that the interpretation of autism as non/epidemic is central to the autism-vaccine controversy. According to Baker, two explanatory frameworks have risen to take the place of the Freudian 'refrigerator mother' hypothesis.

The first framework posits that autism is neurodevelopmental, similar to Down Syndrome or Cerebral Palsy. This premise is adhered to by the majority or 'mainline' medical community of medical professionals, clinical researchers and therapy providers.

The neurodevelopmental framework conceives of autism as 1) biological and likely to be primarily genetic, 2) a spectrum of disorders, with different manifestations, but the same etiology, 3) not curable, but treatable in the form of rehabilitative therapy 4) best treated when detected early.

The second framework conceives of autism as biomedical. Considered unorthodox, this framework has been established by an ‘alternative’ community, comprised primarily of parent-advocates, but also includes some therapy providers and personal injury lawyers. Within this alternative biomedical framework, autism is conceived of as 1) a heterogeneous amalgam of disorders, with similar manifestations but different etiologies and 2) treatable by different means, and sometimes curative depending on the etiology. Most importantly, it is this ‘alternative community’ (primarily parent advocacy groups) that is credited with advancing the premise that rising ASDs rates constitute an ‘epidemic.’

For the mainstream of medical professionals, researchers and therapy providers, the soaring rates of ASDs diagnoses represent, at least *in part*, the logical outcome of efforts made to improve early detection mechanisms and thus offer the best hope for rehabilitative treatment. These efforts have led to legislation that bolsters the agenda of early detection and rehabilitation. In 1991, Congress added autism to the Individuals with Educational Disabilities Act. Additionally, over half of all U.S. states now have insurance mandates for ASDs. Only four states are without ASDs coverage (Adams, 2010). An increase in diagnostic rates following legislative and public awareness efforts is not unique to autism: depression and anxiety have both followed similar trajectories (Berndt, Denoncourt & Warner, 2009). However, this increase in ASDs rates has led to a disparity

between the number of parents requesting therapy, and the number of available ASDs therapy providers. As Berndt et al. (2009) explain:

“What has been frustrating to the mainline community, however, is the gap that all too frequently has opened up between rising demand for and limited supply of autistic therapeutic services, which has resulted in long queues and office visits with physicians unfamiliar with the condition and its treatment. Lacking the institutional resources to solve this quandary, those in the mainline community have turned to each other and to the Internet. (Baker, 2008).” (p. 134).

2.2.1 The MMR Vaccine Controversy in the UK

Objections to vaccination are not unique to the present. The first compulsory vaccination law, enacted in England in 1853, required that every infant be vaccinated against smallpox within the first three months of life. Antivaccination groups emerged promptly. Durbach (2005) explains that these groups, largely comprised of poor and working class individuals, opposed compulsory vaccination on several grounds. First, antivaccinationists were concerned about the safety of the vaccine, as the smallpox vaccine involved a scoring process that sometimes left children disfigured or, in the worst-case scenario, dead from complications. Second, the vaccination laws, if broken, harshly penalized poor and working class individuals who were often unable to pay the mandatory fine and subsequently imprisoned. Lastly, the introduction of mandatory vaccination represented a fundamental shift in English conceptions of the pristine nature of bodies, as well as the profession of medicine, the state, and the intersection of the two. Durbach argues that,

“Vaccination, as the first continuous public-health activity undertaken by the state, ushered in a new age in which the government began to provide health care to the general public. Significantly, the policy of universal compulsory vaccination also marked an important shift away from sanitary approaches to the persistence of dirt and disease and toward preventative medicine. (p.17).

Nearly 150 years later, England once again serves as the stage upon which vaccine controversies are being played out. In 1998, Andrew Wakefield and colleagues published a notorious study of twelve children with both gastroenterological disorders and autism in the *Lancet*. In the article, Wakefield et al. (1998) reported that eight of the twelve autistic children in the study began to manifest ASD symptoms shortly after receiving the combination Measles, Mumps and Rubella (MMR) vaccine. The theory of “autistic enterocolitis” born from this paper, colloquially referred to as the “Leaky Gut theory,” proffered that children with certain gastroenterological disorders do not have strong enough immune systems to cope with the introduction of three live viruses at once. Though the paper did not explicitly argue that the MMR vaccine and autism were causally linked, the authors stated that,

“Further investigations are needed to examine this syndrome and its possible relation to the vaccine.”

Despite the measured tone of the above quote, Wakefield attended large press conferences after the publication in which he discussed, at length, the possibility of a link between autism and the MMR vaccine. (Boyce, 2006). He told a reporter that he could not ‘support the continued use of these three vaccines given in combination until this issue has been resolved.’ (Campbell, 2007).

The study was later deemed scientifically and ethically problematic. An investigative reporter for the *Sunday Times* revealed that most of the children in the study had not been referred to Wakefield by a physician, but rather, by a solicitor named Richard Barr. (Barr was trying to build a case against MMR vaccine manufacturers.) Additionally, it was revealed that Wakefield was engaged in paid research collaboration with Barr prior to the Lancet publication, but had failed to disclose that conflict of interest as required by the *Lancet*. (Deer, 2007). In 2010, the Wakefield et al. study was officially deemed fraudulent, retracted from the journal, and Wakefield struck off the UK medical registry (Godlee & Marcovitch, 2011).

Though the Wakefield et al. study has been thoroughly discredited by the medical establishments in both the UK and U.S., the damage is considered done: in the UK, MMR vaccination rates following the Wakefield publication have dropped from 92 to 73 percent—well below the ‘herd immunity’⁵ level recommended by the World Health Organization (Associated Press, 2007). Even Prime Minister at the time, Tony Blair, refused to disclose whether he had vaccinated his son with the combined MMR vaccine, amid rumors that he had traveled to France so his son could receive separate doses of each vaccine (Campbell, 2007). In the U.S. the drop in MMR vaccination rates has not been as pronounced, though there were more outbreaks of measles in 2011 than any year since 1996⁶ (“Measles - United States, January -- May 20, 2011”, 2011).

⁵ ‘Herd immunity’ refers to the phenomenon wherein individuals who cannot be vaccinated for medical reasons benefit from the collective immunity of the masses. A baseline percentage of the population must be vaccinated in order for herd immunity to take effect.

⁶ Of the measles cases reported, 89 percent of patients had not received the MMR vaccine (Centers for Disease Control, 2011).

2.2.2 The Thimerosal Controversy in the U.S.

Though U.S. anxiety about mercury toxicity predates the MMR controversy in Britain by nearly thirty years, it was the latter controversy that helped realize the U.S. thimerosal controversy. Baker (2008) and Clarke (2009) argue that the thimerosal controversy did not necessarily extend from the UK MMR issue, but the two issues were rooted in the same fundamental concern and served to reinforce each other. Thimerosal is a mercury-containing vaccine preservative, introduced in the 1920s when the primary vaccine safety concern was bacterial contamination (“Thimerosal in Vaccines,” 2011). It was prized for its ability to safeguard against bacterial contamination in vaccines without compromising the potency of the live viruses contained within the vaccine (Jamieson & Powell, 1931).

In the 1960s and 1970s, two newsworthy environmental mercury poisonings occurred that raised public awareness of the damaging potential of mercury (Baker, 2008). The first event became known as the ‘Minamata Bay disaster.’ In Japan, a chemical company had been releasing methylmercury into wastewater, poisoning the fish and the individuals who ingested them. The disaster was made public when an American photographer exhibited a photographic essay consisting of Japanese individuals afflicted with mercury poisoning. (Hughes, 2000). Shortly thereafter, a second mercury-related disaster occurred in Iraq. In 1971-2, seed wheat used to make bread was contaminated with mercury-containing fungicide, resulting in mercury poisonings and deaths (Bakir, Damluji, Amin-Zaki, et al., 1973). Following these disasters, numerous U.S. studies were conducted to determine safe levels of methylmercury (particularly for expectant mothers.)

Confusingly, several of these studies arrived at different conclusions and made different recommendations for safe methylmercury levels, though the general agreement was that methylmercury was in fact more toxic to humans than previously thought. At the time of the poisonings and subsequent safety reviews, no discussion of a link between thimerosal and autism was mentioned; such discussions only occurred in 1999, after the Wakefield publication, and a Congressperson's call for the FDA to assess mercury content in its products. It was determined over the course of numerous interorganizational vaccine safety panels that there was no evidence to suggest that thimerosal in vaccines was causing harm; however, it was recommended that it should nonetheless be removed from vaccines for the sake of caution. The American Academy of Pediatrics stated in a press release:

“Parents should not worry about the safety of vaccines. The current levels of thimerosal will not hurt children, but reducing those levels will make safe vaccines even safer.”

The recommendation for thimerosal removal, along with the contradictory press release above, was exceedingly confusing to parents and damaging to public confidence in the safety of vaccination. As Berndt et al. (2009) explain,

“Many parents, frightened by the sudden change in policy and perhaps generally aware of news concerning the vaccine scares in the United Kingdom, reasoned that thimerosal was being removed because it was harmful. Fueled by additional support from parent groups and religious organizations opposing compulsory vaccination in general, the Wakefield phenomenon began to erode public trust in the U.S. vaccine delivery system. (p. 147).

2.2.3 Antivaccination Websites

According to Baker's (2008) historical analysis, the Internet was an essential means for transporting the UK-MMR controversy across the Atlantic to the U.S., where it converged with the thimerosal controversy. With an estimated 80 percent of Internet users utilizing the web to conduct health-related information searches (The Pew Internet and American Life Project, 2011) attention is increasingly being paid to the pool of antivaccination websites that has continued to grow since the confluence of the UK-MMR and U.S.-thimerosal controversies. In a MayoClinic research report on the future of vaccine development, Poland, Jacobson & Ovsyannikova (2009) describe the antivaccination lobby as a 'radical' source of distraction for the medical community in their quest to educate the public and legislators about vaccines, and point to antivaccination websites in particular as an impediment to vaccine uptake. They state,

“...the proliferation of Internet sites that post inaccurate and misleading information that unsuspecting parents read and make decisions upon similarly adversely impacts decisions to receive vaccines.” (p. 3241).

Internet researchers' findings support Poland et al. in their identification of antivaccination websites as a significant obstacle for provaccination efforts. Wolfe & Sharpe (2005) found that when one conducts an Internet search for the term “vaccination,” 31 percent of the search results are actually antivaccination websites as compared to 21 percent provaccination websites.⁷ Similarly, Abbott (2000) found that searches for the term ‘MMR vaccination’ yielded 43 percent antivaccination websites,

⁷ Internet searches for the “immunization” yielded 98 percent provaccination websites. Antivaccination groups dispute that vaccines produce immunity. (Wolfe & Sharpe, 2002).

and Davies, Chapman & Leask (2001) concluded that all of the first ten Google search results for ‘vaccination’ were antivaccination websites.

Content and design analyses of antivaccination websites have noted that one of the primary organizing strategies employed is a striking similitude to official scientific websites (Davies et al., 2003; Wolfe, Sharpe & Lipsky, 2002) including a title denoting national or international status, extensive reference lists and claims of being ‘nonpartisan’ information sources regarding the vaccine debate. Davies et al. (2003) state that, ‘Overall [the content and design] produced a spectre of the existence of masses of data on the dangers of vaccination.’ (p. 22).

Despite appearances of scientific credibility, Davies et al. (2003) and Wolfe et al. (2002) deem the antivaccination websites studied to be highly unscientific in nature due to unsourced scientific claims, the inclusion of non peer reviewed and alternative scientific literature, and reinterpretations of peer reviewed medical studies that are at odds with the interpretations of the studies’ authors. Wolfe et al. found that the common claims made by these websites are that 1) vaccines cause idiopathic illnesses (illnesses of unknown origin); 2) vaccines actually erode immunity rather than produce it; 3) adverse vaccine reactions are underreported; and 4) compulsory vaccination is profit-driven. Additional components of antivaccination websites include 1) links to other antivaccination websites; 2) information for the legal avoidance of vaccines; 3) use of ‘emotional appeals’ including the first person narratives of parents who believe their child has been harmed by vaccination.

2.2.4 (Im)Balanced Mass Media Coverage of AVC

The assumption inherent in much of the literature on vaccine communication is that 1) nonvaccinating individuals do not have access to adequate information on vaccination and/or 2) nonvaccinating individuals have fallen victim to misinformation campaigns waged by antivaccination organizations. Given that the public receives much of its information about health controversies from media stories, much attention has been paid to how the media cover news stories about vaccination, such as the Wakefield and thimerosal controversies. One of the dominant criticisms made of media coverage of vaccine-related stories is the ‘balance-as-bias’ phenomenon. Entman (1989) describes ‘balance’ as one of the guiding principles adhered and aspired to in the traditional model of journalism. He says,

“Balance aims for neutrality. It requires that reporters present the views of legitimate spokespersons of the conflicting sides in any significant dispute, and provide both sides with roughly equal attention.” (p. 30).

Boykoff & Boykoff (2004) argue that in instances of publicized disputes, scientific or otherwise, media coverage that attempts to give equal and unbiased attention to both sides can sometimes, in doing so, create bias. Here, the word ‘bias’ is not used to describe an ideologically predisposed media, but rather an ‘informational bias.’ This sort of bias occurs when media give equal coverage to two (or more) sides of a scientific debate when consensus of the scientific community heavily favors one side. In applying the balance-as-bias phenomenon to the AVC, Clarke (2009) points out that in 1998, there was not yet scientific consensus about whether autism could be linked to vaccines. Thus, media reportage adhering to the journalistic norm of ‘balance’ did not yet conflict with

the second journalistic norm of ‘accuracy.’ But after scientific consensus was formed through a series of vaccine safety panels, ‘balanced’ media coverage preempted scientifically ‘accurate’ coverage. According to some, this balance-as-bias phenomenon lends scientific credibility to otherwise non-credible sources and viewpoints, and in doing so can create a heightened sense of risk amongst the public (Dearing, 1998). Risk is an important factor in parental decision making: in a survey regarding public perception of vaccine risks, Jenkins-Smith, Silva & Song (2010) found that parents who believe that vaccine risks are equal to or greater than vaccine benefits (roughly one third of participants) are significantly less likely to report that their children had received all the recommendation vaccines.

2.2.5 Heightened Risk, Lowered Trust

Scholars across fields argue that late/post modernity is characterized by a growing preoccupation with the calculation of risk. This preoccupation has given rise to the term ‘risk society’—a concept popularized by Ulrich Beck and Anthony Giddens. They argue that risk society is not the product of an increasing number of risks, but rather, a different *sort* of risks. Whereas risks to human life used to be viewed as the inevitable outcome of a society of scarcity (where risks were largely natural, such as draught and famine) they are now understood within the paradigm of a society of wealth (where risks are often human-produced, like car accidents and obesity). Beck (1992) explains that,

“In advanced modernity the social production of wealth is systematically accompanied by the social production of risks. Accordingly, the problems and conflicts relating to distribution in a society of scarcity overlap with the problems

and conflicts that arise from the production, definition and distribution of technoscientifically produced risks. (p. 19).

Given the preoccupation with risk in a society of wealth, it is no surprise that a process for quantifying risk has emerged and become immensely popular. Risk communication is described as an ‘interactive process of exchange of information and opinion on risk’ among interested parties; it is used as a multidisciplinary tool for quantifying the risks versus benefits for a range of issues from nuclear energy plants to financial markets, though its most common application is public health-related issues. (“Risk communication,” 2011).

Risk is a theme that runs throughout vaccine discourse, and risk communication is the instrument of choice for health officials attempting to communicate with the public. Hillier (2006) points out that risk *miscommunications* often arise when risk ‘assessors, managers and communicators’ mistakenly assume that they are operating from within the same ‘cultural and conceptual framework’ as the public with whom they are communicating. Hillier says that,

“To those trying to manage or regulate risks, public reactions sometimes seem bizarre. To the public, the behavior of those supposedly in charge can seem no less strange. (p.1)

Following this logic, parents may have a framework for assessing the risks versus benefits of vaccination that is incommensurable with those of health professionals and public health officials. Part of this incommensurability in framework is thought to stem from very effectiveness of the vaccines themselves. Commonly referred to as ‘a victim of their own success’ (Allen, 2007; Ball, Evans & Bostrum, 1994; Colgrove & Bayer, 2005)

vaccination programs have been so effective in decreasing or eradicating certain preventable illnesses that the risks of vaccinating have become more salient than the risks of catching, for example, the mumps. For a public health official trained to foreground the *collective* risk of contagious disease, the risks of a given vaccine may seem so low as to be negligible. However, for a parent conditioned to make decisions based on the *individual* risk to her/his child, the risk may not be acceptable—especially given the low rates of vaccine-preventable illnesses, and the current 1 in 110 rate of ASDs in children (“Autism spectral disorders,” 2011).

Closely connected to the thread of risk that runs throughout vaccine communication literature is the concept of trust: in government, in science and its experts, in the media to provide reliable information, etc. Most discussions of trust in vaccine communication literature are framed in terms of a lack or waning of public trust. Leach and Fairhead (2007) point out that this breakdown of trust is often theorized as a move toward a less deferent society, one in which ‘expertise’ (especially the expertise of medical scientists and professionals) is no longer granted an axiomatic credibility, and instead skepticism abounds. They state,

“If such trust is breaking down, such analyses suggest, this signals a move into a different, late modern or post-modern societal order. (p. 18).

Many scholars view this widening lack of trust as a central problem in vaccine communication (and also in public understanding of science more generally.) Bucchi (1998) points out that a defining feature of modern science is its ‘greater autonomy from the general public than in the past.’ (p. 1). According to Bucchi, with this greater autonomy comes a greater ‘knowledge gap’ between the general public and scientific

experts, further problematizing communication between the two. Though expert sources are increasingly used to disseminate information to the public, the public ‘believes in them less and less.’ (Limgoes, 1993). Focusing on the UK MMR controversy, Boyce (2006) points out that scientific experts often called upon their own parental experiences with vaccination in addition to, or instead of, referring to their scientific expertise. This is perhaps indicative of a move towards narrowing the knowledge gap by speaking to parents ‘in their own language’ and avoiding the scientific jargon denoting the expertise that parents are alleged to trust less and less. In addition, according to Gross (2009) and Kaufman (2007) parents are increasingly encouraged to conduct their own research, under the logic that the institutions purporting to protect them and their children (the government, the FDA, the American Academy of Pediatrics, etc.) have failed to deliver on their promises to keep children safe from vaccine harm. When conducting independent research, parents are met with an expanse of confusing and conflicting information, within which vaccine experts’ voices easily become muffled, or ‘just one more opinion.’ (Kaufman, 2007).

3. METHODS AND JUSTIFICATIONS

3.1 Methods Overview

This paper seeks to rhetorically analyze the AVC through the lens of postmodern medicine. There are several interrelated reasons for this. The first reason is that postmodern medicine is a nascent theory, and accounts of it to date are relatively sparse. Frank (1995) and Morris (1998) make the call for expanded inquiry to advance theoretical understandings of postmodern medicine, and this project seeks to contribute to that end. Additionally, extant accounts of postmodern medicine to date have tended to be broad and overarching. Approaching the AVC as an illustrative case study can help concretize the theory of postmodern medicine. Likewise, scholarly accounts of the AVC tend to be fragmented. AVC research typically isolates one sector of a broad and complex picture for in-depth analysis. While many of these accounts are useful for understanding a particular dimension the AVC, (e.g. content and design analyses of antivaccination websites, studies of the role of expert sources within mass media coverage, and the historicizing of mercury anxieties in the U.S., etc.) the isolation of one distinct component of the controversy fragments the broader context—a context that this project argues is particularly well elucidated by the theory of postmodern medicine. By situating the AVC within the paradigm of postmodern medicine, a meaningful sense of context can be attained—specifically, how the following three elements have presented themselves within the AVC, the role they have had in shaping it and what they portend for the persuasive functioning of medicine in a postmodern era: the weakening of the biomedical narrative, use of the Internet to seek and share health-information, as well as the transformed nature of patient-physician (i.e. ‘consumer-provider’) relationships.

Secondly, scholarly accounts of the AVC have thus far obscured or neglected to attend to the role of persuasion, and to an extent, the same can be said about scholarly accounts of postmodern medicine. Though some studies indirectly address the role of persuasion within the debate, the way persuasion is conceptualized in the literature is often limitative. Specifically, persuasion in the AVC is conceived of as taking place in one direction: from anti-vaccination groups to parents. This view presupposes that parents who decline vaccination have been misinformed about vaccination and its ‘very acceptable’ risks by radical and irrational antivaccination efforts. The dominant research question underlying this literature is: how is it that antivaccination efforts have *succeeded* in persuading parents not to vaccinate? By framing the question as such, another equally important question is buried: how is it that provaccination efforts have *failed* at persuading parents to vaccinate? In order to answer latter question, the provaccination efforts of the ‘mainline’ medical establishment—which have received comparatively little attention to date—must be explored.

In addition to a restrictive conceptualization of persuasion within the AVC, highly visible rhetors from within the debate are noticeably absent from scholarly accounts: actress Jenny McCarthy and pediatrician Dr. Paul Offit. These two rhetors are widely acknowledged to be two of the most vocal public participants in the AVC, advocating for antivaccination efforts and provaccination efforts, respectively. McCarthy is an actress whose son was diagnosed with autism in 2005. Since that time, she has used her celebrity platform to promote claims that autism is environmental in etiology, and specifically attributable to vaccines. McCarthy has written two books (one of which is a *New York Times* bestseller) on the subject of autism, its etiology and ‘alternative’ curative

treatments. She has regularly appeared on programs such as *Larry King Live*, *Oprah*, *Frontline* and *The Doctors* to debate medical professionals on issues of vaccine safety generally, and the autism-vaccine link specifically. She is also the president of the nonprofit organization ‘Generation Rescue’—a foundation that seeks to provide information on vaccines, autism and its possible curative treatments.

Just as Jenny McCarthy epitomizes the increasingly common celebrity expert, Dr. Paul Offit represents the traditional medical expert. He is a pediatrician, immunologist and Professor of Vaccinology and Pediatrics at the University of Pennsylvania. He helped invent the rotavirus vaccine, and advises the Centers for Disease Control on vaccination issues (as such, he is criticized by antivaccination groups as having profit-driven motives for his provaccination efforts.) Like McCarthy, he is also an author of popular books, two of which seek to correct what he considers to be misinformation about vaccines and autism. He has made appearances on television and radio programs like *The Colbert Report*, *Dateline* and NPR’s *Talk of the Nation*. In addition to appearances on popular media, he regularly publishes in peer-reviewed medical and scientific journals. He has become one of the most prominent figures in the AVC, and claims to regularly receive death threats as a result of his provaccination advocacy. Because he is highly visible within the debate, and thoroughly entrenched within the medical profession, he is an ideal rhetor for inclusion in this project; Offit’s persuasive attempts can yield insight into how a ‘traditional’ medical expert perceives, responds and adapts (or does not adapt) to the challenges faced by medical professionals in an era of postmodern medicine.

3.2 Cluster Criticism

In *A Rhetoric of Motives* (1950), Kenneth Burke describes rhetoric as ‘the use of words by human agents to form attitudes or to induce actions in other human agents.’ (p. 41).

One Burkean approach for analyzing rhetoric is called ‘cluster criticism.’ This is a process by which the critic discovers the significance that particular key terms/elements (discursive or nondiscursive) hold for the rhetor by first charting the associational terms/elements that recur around the key terms/elements. Burke discusses the cluster approach for rhetorical analysis in the *Philosophy of Literary Form* (1941). He explains,

“Now, the work of every writer contains a set of implicit equations. He uses ‘associational clusters.’ And you may, by examining his work, find ‘what goes with what’ in these clusters—what kinds of acts and images and personalities and situations go with his notions of heroism, villainy, consolation, despair etc.” (p. 20).

By charting out ‘what goes with what’ in a rhetorical artifact or collection of artifacts comprising a discourse, the critic can gain insight into the following: the meanings that key terms hold for the rhetor, the way that relationships among key terms help structure each term’s meaning, the rhetor’s strategies for forming attitudes/inducing action in their audiences and ultimately, the rhetor’s worldview and the implications of holding such a worldview (Foss, 2009). Cluster criticism is an approach particularly well suited to this project, as this project seeks to attend to the thus far neglected role of persuasion on both the antivaccination and provaccination sides of the AVC, and to determine how rhetors (one medical expert and one non medical expert) conceive of (and exemplify/adapt to/resist) the defining elements of postmodern medicine described earlier: the weakening

of the biomedical narrative, the use of the Internet to seek and share health information, and the transformed nature of patient-physician relationships.

In order to conduct a cluster criticism, the critic must first select the rhetorical artifact(s) for analysis. According to Foss (2009) it is important that the rhetorical artifacts are long and complex enough to allow for the charting of associational clusters. In this case, the rhetorical artifacts selected for analysis are four books: two written by Jenny McCarthy and two written by Dr. Paul Offit. Jenny McCarthy's books that will be analyzed are: *Louder than Words: A Mother's Journey in Healing Autism* (2007) and *Mother Warriors: A Nation of Parents Healing Autism Against All Odds* (2009). (The former peaked at #3 on the *New York Times* bestseller list.) Dr. Paul Offit's two books that will be analyzed are: *Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure* (2008) and *Deadly Choices: How the Anti-Vaccine Movement Threatens Us All* (2011). These books have been chosen over McCarthy's and Offit's numerous media appearances because the books are longer and more likely to yield associational clusters, and also because it is reasonable to assume that the topics discussed in their media appearances echo the topics discussed in their books. The research questions that will guide the analysis are listed below. To answer the following questions, associational clusters that recur around the key themes of postmodern medicine will be identified and analyzed.

RQ₁ What associational clusters recur around the key element of *the weakening of the biomedical narrative*?

RQ₂ What associational clusters recur around the key element of *Internet use for health-related purposes*?

RQ₃ What associational clusters recur around the key element of *the transformation of patient-physician relationships*?

4. ANALYSIS

4.1 Overview of McCarthy's texts: *Louder Than Words* and *Mother Warriors*

Jenny McCarthy's first book on the subject of autism, *Louder than Words: A Mother's Journey in Healing Autism* is her highest selling book to date, having reached number three on the *New York Times* bestseller list. On Amazon.com, the book receives a user rating of four out of five stars. The book is relatively short, comprising two hundred (small-sized) pages of far-spaced text and generous page breaks. It begins with a foreword and an introduction written by two medical professionals: David Fineberg, whose credentials are listed as "MD, medical director of Resnick Neuropsychiatric Hospital at UCLA, " and Jerry Kartzinell, whose credentials are listed as "MD, FAAP; Board-certified pediatrician."

Fineberg's foreword relays basic information about autism: its broad definition, treatment, causes and its increasing incidence. The foreword also includes a brief introduction to Jenny McCarthy as a public figure. Fineberg mentions that many points of contention exist with regard to autism's causes, growing rates of diagnosis and its forms of treatment. Less focused on the medical details of autism, Kartzinell begins his introduction to the book by describing his experience of watching his son "slip into the world of autism after receiving his first mumps, measles and rubella (MMR) vaccine." (p. xv). He goes on to describe the nutritional interventions that helped 'recover' his son from autism. He concludes by saying that "Autism is not a dead-end diagnosis. It is the beginning of a journey in faith, hope, love, and recovery." (p. xvii).

The bulk of the book chronicles McCarthy's experience with her son's autism, starting the morning of his first seizure, his subsequent diagnosis and treatment and

ultimately, his recovery. Mention of vaccination does not occur until page 83, midway through the text. The book concludes with a “What to Do Pamphlet” for parents (mothers, specifically) whose children have been diagnosed with autism. The pamphlet includes information on traditional behavioral therapy, alternative therapies (such as diet and supplementation), vaccination and a list of websites for perusal.

McCarthy’s second book, *Mother Warriors: Healing Autism Against All Odds*, is of similar length to the first, also comprised of small pages and far-spaced text. On Amazon.com it receives a user rating of four-and-a-half out of five stars. Like McCarthy’s earlier book, *Mother Warriors* also begins with a foreword written by a medical professional. His name is Jay N. Gordon and the credentials that follow his name are “M.D., F.A.A.P., I.B.C.L.C, F.A.B.M.” Gordon uses the foreword to suggest that parents exercise caution with regard to vaccines, and to remind readers of the close connection between the American Academy of Pediatrics and vaccine manufacturers. He then describes the harmful effects of both mercury and aluminum content in vaccines. He ends with the statement “Medical interventions have caused many cases of autism. Jenny McCarthy presents a case for medical interventions that can lead to recovery. This book is meant to be read not with sadness but rather with lots of hope for the future.” (p. xviii).

Throughout the body of the text, McCarthy recounts her media appearances, subsequent to the first book’s publishing, that dealt with subject of autism and vaccines. These programs include *The View*, *The Oprah Winfrey Show* and *Larry King Live*. Roughly half of the book is focused on McCarthy’s experience “raising awareness” about autism and its link to vaccines; the rest of the book contains selected mothers’ testimonials of their experiences of autism diagnosis, treatment and recovery, followed

up by McCarthy's commentary. (These contributors are the women to whom the title *Mother Warriors* refers.) As compared to *Louder Than Words*, *Mother Warriors* contains much more pointed criticism of the Centers for Disease Control, American Academy for Pediatrics and the mainline medical establishment in general. The book also argues the autism-vaccine link more explicitly, and McCarthy and the other "mother warriors" describe their frustration with the mainline medical community for not legitimating the alternative treatments that they claim have helped 'recover' or 'undiagnose' (the two terms are used interchangeably) their children from autism. The book concludes with a state-by-state list of DAN (Defeat Autism Now!) doctors, who practice alternative therapies for the treatment of autism.

4.2 Overview of Offit's texts: *Autism's False Prophets* and *Deadly Choices*

Autism's False Prophets is Paul Offit's third sole-authored book on the subject of vaccines, and his first book to focus exclusively on the autism-vaccine controversy. (His two previous books on the subject of vaccines are historical recountings of Maurice Hillman, called "Father of Modern Vaccines" and the Cutter Incident, wherein tens of thousands of children were inadvertently injected with live polio virus.) *Autism's False Prophets* is a three-hundred page book, including roughly fifty pages of notes and citations.

The book opens with a prologue, which Offit uses to describe the volume and intensity of hate mail he receives as a result of his vaccination advocacy. He also uses the prologue to describe his early experience with medicine: a playground accident resulting in a splenectomy, as well as the treatment of his club foot, which resulted in an extended hospital stay in a shared room with multiple polio-ridden children. He also details an

incident early in his career as a doctor, in which an infant patient died from the rotavirus. According to Offit, these were the formative experiences that lead him to want to pursue a career in medicine, and in virology and immunology more specifically.

The remainder of the book reads much like a historical analysis of the autism-vaccine controversy in chronological order, beginning with Andrew Wakefield's 1998 study, through the "rise and fall" of the mercury hypothesis and the autism-vaccine litigation. The book then moves on to a discussion of the status of science (i.e. "scientific truth") in the courtroom, in the media and in the public discourse more generally. The epilogue concludes with a line-by-line analysis of Jenny McCarthy's appearance on the *Oprah Winfrey Show*.

Offit's second book, *Deadly Choices*, is similar in length and format to the first. In the same way that McCarthy's second text is a more pointed criticism of the medical community, Offit's second text is a more pointed criticism of the anti-vaccine movement, which he considers to be largely spurred on by personal injury lawyers, scandal-hungry media and the parents who have been misled as a result. He opens the book by stating that "There's a war going on out there—a quiet, deadly war... On one side are parents... On the other side are doctors... Caught in the middle are children." (p. ix-x).

Like its predecessor, *Deadly Choices* is also arranged in chronological order, and reads like a historical analysis of the anti-vaccine movement as a whole. The analysis commences with public figures that voiced concerns about the safety of the Pertussis vaccine in the 1960s-1980s, and then focuses attention to the MMR vaccine controversy. Much time is spent discussing the workings of the Vaccine Court and the Vaccine Injury Compensation Program (VICP.) He suggests that Vaccine Court has been overly

acquiescent to parents for the purpose of preventing parents from suing vaccine manufacturers directly, and thus restricting children's access to vaccines. He discusses, at length, the Omnibus Autism Proceedings, wherein five thousand cases were to be tried at once like a class-action lawsuit since the Vaccine Court lacked the resources to try them all individually as was customary. He spends subsequent chapters discussing media personalities like Jenny McCarthy who speak out against vaccines, and describes what he considers to be logical inconsistencies and medical inaccuracies in their positions. A significant portion of the text is used to discuss the specific, technical medical components of vaccines and how they function within the human immune system. The book concludes with an epilogue calling for the recapturing of the "immunological cooperative" sentiment that was present during the polio epidemic, which was treated as a "shared disease."

4.3 Charting of Clusters

4.3.1 McCarthy's texts: Clusters recurring around the theme of the Weakening of the Biomedical Narrative

The weakening of the biomedical narrative is considered one of the most fundamental features of postmodern medicine. According to Frank (1996) and Morris (1998), the biomedical narrative is weakened by a number of factors, especially patients' tendency to desire a more prominent role in constructing narratives of health and illness. This desire is evident in both *Louder than Words* and *Mother Warriors*. The primary associational clusters that recur around this theme are *voice* and *instinct*. These two terms are often used in close proximity to one another to describe experience(s) of frustration or dissatisfaction with the medical community.

Voice is a term that figures prominently in both of McCarthy's texts, used both in

the singular, literal sense and a collective, figurative sense. The term “voice” often occurs in tandem with the term *instinct*. The term voice tends to be used with a particular emphasis on volume (also evident in the title *Louder than Words*). McCarthy frequently writes that she and other mothers are “screaming,” “yelling,” or “crying out,” and yet they are likely to be “ignored” or “dismissed” by doctors and other medical professionals.

References to screaming, yelling and the like begin as McCarthy recounts her experience with hospital staff, after her son is admitted for seizures. In this context, voice is used literally. The term functions to convey her perception of the hospital staff as incompetent, impersonal and dangerous. McCarthy’s use of impassioned profanities contrasts starkly with the sterilized medical language that McCarthy first encountered in the emergency room, which she terms “big fat medical words.” (p. 19). McCarthy consistently employs impassioned language to express her displeasure with a number of experiences: when her son was examined by resident interns as opposed to a neurologist, when he was injected with Valium as a short-term treatment for seizures, and when she was told that a heartbeat monitoring machine (which she wanted to purchase) was not medically necessary. The text from which these clusters were extracted follows.

They ignored me and started with yet another barrage of questions. (p. 19, *Louder Than Words*)

She started using big fat medical words, and I started screaming, “Please don’t let him go into cardiac arrest. They immediately injected him with more Valium and I thought, how much Valium can a two year old take before he ODs? Plus, they kept giving him Valium and he continued to seize. Was that really the best thing for the job? I needed answers, and I wanted them *now*.” (p. 19, *Louder Than Words*)

I said, “I don’t care if you won the fucking Nobel Peace Prize. I want someone with a degree in neurology who knows every part of the goddamn brain.” They ignored me and began to tell me that they were going to take Evan for an MRI. I replied, “Well, if you’d read the damn report I handed you when we got here, you would have seen we already had one!” (p. 19, *Louder Than Words*)

The nurses ran in and injected him with more Valium. I screamed, ‘Why do you keep putting that shit in him? It only works for a short time. There has to be something better!’ It’s amazing how easily medical staff ignores crying, yelling mothers. (p.22, *Louder Than Words*).

I bolted up and ran into the middle of the nurse's station and started screaming like Shirley Maclaine. 'My son is seizing again! My son is seizing again! My son is seizing again! Do something to make these stop!' 'Maam, calm down,' the nurse said. She ran into the room to inject him with—guess what? That's right, more Valium. I screamed even louder. "My son has gone into cardiac arrest and has seized six times today, and I still haven't seen one fucking neurologist! Not one fucking neurologist has come into this fucking room, and my son won't stop seizing! Find the fucking doctor now! Go! Find the fucking doctor!" (p. 22, *Louder Than Words*).

When I called the company, they said it [heartbeat monitoring machine] was for hospital use only, by prescription from a doctor who had to clearly state the child was in dire need. I called my pediatrician, and he attempted to tell me how he didn't think it was necessary. Before he could even get the word 'necessary' out, I screamed, "You have no fucking idea what I have through in the past week. I need this goddamn machine, so fill out the fucking prescription and fax it to me now!" (p. 38, *Louder Than Words*).

In addition to the above references to literal voice, McCarthy makes numerous references to voice in figurative, collective terms later in the text. In the figurative and collective context, voice is used to describe a collective of mothers who believe that 1) their child's autism is causally related to vaccine and 2) nontraditional medical treatments helped 'recover' their child from autism. In the collective sense, voice is a term used to describe frustration and disillusionment that parents experience when the mainline medical community's explanation of autism causes and treatments do not align with parents' experiences with their own child's autism. When this collective group of mothers advance their narrative experiences of autism (that differ from the medical community's narrative) McCarthy states that they are "silenced...called stupid and ignorant..." (p. 126-127, LTW). As in the earlier use of voice, 'ignore,' 'dismiss' and 'oblivious' are terms that occur in close proximity to the collective use of voice. Those identified as being primarily responsible for the ignoring, dismissing and silencing the collective voice of mothers are pediatricians, neurologists and the American Academy of Pediatrics. The text from which these clusters were extracted follows.

It was in this room [of mothers with autistic children] that I realized I would someday be a voice for mothers of autistic children. (p. 118, *Louder Than Words*)

Before I could even say hi [mothers of autistic children] started telling me yet again about diet, detox and how I needed to be the one to spread the word about autism being an epidemic. (p. 126-127, *Louder Than Words*)

I knew at home millions of mothers had been waiting years for what was coming in the segment after the commercial break. Mothers who have been silenced, mothers whose child's own pediatrician had called them stupid and ignorant, mothers who had been accused of causing their child's autism with their own negligence, mothers who had waited years for one person to break through in the media and say what they have been screaming for a whole decade. This wasn't my moment in the spotlight coming up. It was theirs. I was their voice and was ready to speak on behalf of these amazing women. (p. 8, *Mother Warriors*).

I felt the collective energy of moms everywhere. I felt them jumping up and down on their couches, I felt them glued to their TV screens, crying and raising up their arms, I felt them calling their own moms on the phone screaming, 'Are you hearing this!? She said it!' (p. 9, *Mother Warriors*).

People we told about the vaccine connection called us crazy and desperate to blame, but we've lived with our children and have watched them suffer. I could understand if only a few mothers were speaking out, but when millions of mothers are screaming that something happened when their child was vaccinated, I think it's time the world listened to what we have to say. (p. 10, *Mother Warriors*).

Some moms worry they didn't scream loudly enough when they had concerns about the vaccination. (p. 15, *Mother Warriors*).

Thank you [to Oprah] on behalf of thousands of moms for allowing me to speak the truth. (p. 17, *Mother Warriors*).

I was about to find out that there were many moms like me who were made to feel stupid for speaking this truth, and I was going to be the one to knock down some walls. (p. 19, *Mother Warriors*).

We had beautiful healthy children who climbed up stairs perfectly fine until one stair caused them to fall. We have witnessed the neurological downfall of our children after certain vaccinations, but when we tell the doctors what we saw, they don't believe us. Can you imagine how frustrating this is? (p. 21, *Mother Warriors*).

Gee, I wonder why there is a crisis between pediatricians and moms. Hmmm... Could it be because they don't listen to us at all when we have a concern, and make us feel stupid? (p. 37, *Mother Warriors*).

We need the AAP [American Academy of Pediatrics] to get of its butt and focus on alleviating the fears and concerns we the parents in this country have. Stop trying to prove us wrong and just listen to us! (p. 53, *Mother Warriors*).

I listened to story after story, and every story was the same: I vaccinated my kid and something happened because then he stopped speaking. I stood on stages and looked out into the crowds of moms who were all screaming the same thing, 'Someone listen to us!' (p. 58, *Mother Warriors*).

I recovered my kid and I have a story to tell!, she yelled. (p. 61, *Mother Warriors*).

While sitting in Larry's studio waiting to go live, I looked over at the people from the AAP and wondered how they could be so blind. I wondered how they could live day to day oblivious to the screams of all these parents. (p. 159, *Mother Warriors*).

A second associational term that clusters around the theme of the biomedical narrative is *instinct*, most commonly referred to as “motherly instinct” but also appears as “mommy radar,” “gut instinct” and “emotional guidance system.” It often appears in opposition to the official medical diagnosis/treatment of autism, or to the practice of vaccination. Occasionally the instinct is possessed by the person: “I have always had very good instincts”. But more often, the instincts possess the person: “My instinct was screaming at me...” One of the prime functions of this instinct is to determine whether or not to trust a medical profession and the diagnoses they offer. For example, McCarthy’s instinct ‘tells her’ not to trust a doctor’s diagnosis of epilepsy, but later ‘screams’ that a neurologist’s diagnosis of autism is correct. Several of the ‘mother warriors’ state that vaccinating their children ran counter to what their instincts were ‘telling them.’ The text from which these clusters were extracted follows.

From the foreword: Jenny’s maternal connection and instincts define motherhood. It is truly not just *louder than words*, it is *stronger than words*. (p. xii, *Louder than Words*).

My emotional guidance system didn’t agree. I blurted out, ‘That just doesn’t seem right... It feels like we’re missing something.’ Honestly, it was my maternal gut instinct that epilepsy was not the end of this road. I felt like there was a highway ramp that everyone was not getting on. I had no other proof at this time to back this up, only a big fat voice screaming, ‘You’re missing the bigger picture!’” (p. 30, *Louder than Words*)

I interrupted the doctor to say, “Is this normal?” “Is what normal?” he said. “The flapping with his hands and spinning. He’s always done it, but ever since his first seizure, it seems like it’s all day long. Does it mean anything?” “No it’s fine, completely normal,” he said. “I don’t know, I just feel like we might be missing something. It’s a gut instinct. I don’t know.” (p. 48-49, *Louder than Words*).

I hoped that this was the doctor I had prayed for—someone who actually knew what the hell he was talking about. My instincts had always been right about people, and if this guy turned out to be a bozo like the last one, I didn’t know what I would do to the medical community. (p. 53, *Louder than Words*).

I still did not want to believe the doctor, though this time my emotional guidance system was telling me he was right. (p. 65, *Louder than Words*).

The doctor said, “You need to relax and trust me.” I did trust him. My mother gut said, ‘trust this man.’” (p.67, *Louder than Words*).

Judging only by my mommy radar, I really liked this neurologist. (p. 81, *Louder than Words*)

He had developed a bad OCD that experts say happens with a lot of autistic children. But I wasn't buying the fact that it had developed on its own, and so intensely....My motherly instinct told me that something was wrong, that I was missing a sign. I was determined to figure it out for Evan. (p.159, *Louder than Words*).

My motherly instinct started screaming at me to go into his nursery. (p. 5, *Mother Warriors*).

My instinct was screaming, "There's more! There's more!" I decided to get a second opinion met with one of the best neurologist in the world. He politely put his hand on me and said "Your son has autism." I died in that moment but my instincts told me that this man was right. (p. 7, *Mother Warriors*).

My life would have been totally different if I had typed it in a different way. But something in side me, my instinct, made me type in "lymphoid nodular hyperplasia AND autism." (p.65, *Mother Warriors*).

Against my better judgment and every mothering instinct I had, I backed down. The nurse brought in the needles and once again, I held my baby down to receive them. Three shots, all containing mercury. (p. 80, *Mother Warriors*)

I really liked this doctor and my mommy instinct said, "He's the one!" (p. 93, *Mother Warriors*)

My motherly instinct at the doctor's office told me that maybe he shouldn't be vaccinated today because his immune system was weak. (p. 123, *Mother Warriors*).

My instincts were screaming that this was right. And looking at the science it was obviously was. (p. 166, *Mother Warriors*).

4.3.2 McCarthy's texts: Clusters recurring around the theme of Internet use for health-related purposes

One cluster that recurs consistently around the theme of Internet use for health related purposes is *Google research*, which is ostensibly different from general internet searching. Jenny McCarthy, and the 'mother warriors' whose testimony she includes in her second book, specifically reference "Google research" rather than "Internet search" or "Internet research." At first glance, this may seem inconsequential, since Google has become a popular term, both in its noun and verb form. It is also the most commonly used search engine by a wide margin. However, here, the construction of Google as an independent institution of knowledge merits interrogation. Conducting research 'on Google' is often referred to by McCarthy as 'attending the University of Google' or

obtaining a ‘doctorate in Google research.’ Here it is worth pointing out that McCarthy and other Mother Warriors use the phrase ‘on Google,’ as opposed to ‘through Google.’ This usage indicates a possible conflation between Google as a search engine (that collects and organizes information) and Google as an autonomous producer of knowledge. The text from which these clusters were extracted follows below.

I decided to start doing some research—and by research, I mean Google. By the end of this book, you will see that I should have a doctorate in Google research, what with all the time I spent online trying desperately to understand what was happening to my baby. The more I read, the more the info reaffirmed for me how wrong the diagnosis (of febrile seizures) was. Nonetheless, I learned on Google that once a child has a febrile seizure, the likelihood of having another one is high. I was scared. (p. 12, *Louder than Words*)

In the week after reading books on autism, I still felt like I needed more. I sat down in front of the computer and Googled “autism.” I was shocked by all the information and statistics I found...after all those statistics, I found a site that said “Autism is reversible.” (p. 82, *Louder than Words*)

What is this correlation between a weakened immune system and autism? I was going to make sure Evan’s immune system got better. It was time to dig and get my doctorate from the University of Google. (p. 166, *Louder than Words*)

When I found out Evan was diagnosed with autism, I had no idea what to do. But I knew I had to do something. So I became a detective. Thanks to a ton of Google research, the support of UCLA and my DAN! doctor, and my friendship with other autism moms, I discovered all the organizations, foundations, therapies and diets that can pull kids out of autism. (p. 195, *Louder than Words*).

I left there looking at my boy and knowing it was up to me to help him. I had to figure it out on my own. So I went home, got on the Internet, and Googled “lymphoid nodular hyperplasia and autism.” My life would have been totally different if I had typed it in a different way. But something inside me, my instinct, made me type in “lympoid nodular hyperplasia AND autism.” I had no idea there was a connection. Then up came Dr. Aruthur Krigsman on my Google. And there in front of me was the connection I had no idea existed and was about to save Kevin’s life. (p. 65, *Mother Warriors*).

Then it happened again. We vaccinated and Elias immediately seized. He seized forty five times within his first year. It was during this time my husband starting researching on Google. (p. 195, *Mother Warriors*).

He wouldn’t respond when his name was called, so we started questioning, Could this be autism? With the research we had begun on Google, the sings started pointing in that direction. (p. 195, *Mother Warriors*).

A second associational cluster that recurs around the theme of Internet health is related to the quest to *find answers*. Much of the text below recounts the process of discovery that has leads to these answers. This process of discovery is undertaken

independently of, and with copious suspicion toward, the traditional medical community. McCarthy and other mothers state that since traditional medicine cannot provide answers, the onus is on parents (mothers) to do so. Numerous references to ‘puzzle pieces coming together,’ getting ‘on the right track,’ having a ‘mountain to climb’ and ‘digging in’ can be seen throughout the text with regard to Internet research. This Internet research is mostly aimed at discovering the unique combination of multiple alternative treatments—much like a puzzle whose pieces have come together—capable of ‘recovering’ an individual child from autism. These medical treatments are not provided by or through traditional medical doctors since behavioral therapy is the only form of treatment presently accepted by the mainline medical community. The text from which these clusters were extracted follows.

I had a big job ahead of me. If the doctors weren’t going to give me answers, I would find them myself. (p. 18, *Louder than Words*).

I clicked on the link and began to read...the information wasn’t what I thought it would be...It was my first introduction to the effect of vaccines. My emotional guidance system was telling me I was on to something. Could this be the injury to the brain the doctors kept asking me about? (p. 83, *Louder than Words*).

As I sat back in my home office, I didn’t know what to do with the information I was reading. Could it be real? Could all of this really be linked to vaccines? I figured in due time, little things would present themselves and lead me to the truth. (p. 84, *Louder than Words*).

I didn’t want to leave my computer that night. I was so thirsty to drink up knowledge that the Internet had to offer. (p. 97, *Louder than Words*).

After educating myself on the diet stuff [from the Internet] I believed that all of his allergies had something to do with autism and not just bad luck. I had no way of proving this yet, but all the puzzle pieces were starting to fit together. I knew I still had a mountain to climb, but at least the first little hill had been a victory. I was even more eager to keep going. (p. 107, *Louder than Words*).

I dug in and continued to do more mommy research. I’ve always hated unanswered questions, and you can be damn sure I was going to get to the bottom of everything that came my way. (p. 140, *Louder than Words*).

What is this correlation between a weakened immune system and autism? I was going to make sure Evan’s immune system got better. It was time to dig and get my doctorate from the University of Google. (p. 166, *Louder than Words*).

I had sympathy for Evan's pain, but after starting my heavy research online, I knew that this extreme reaction meant I was absolutely on the right track. (p. 167, *Louder than Words*).

In the meantime, I decided to find out the connection between yeast, immunity and autism. Why was Evan's immune system so fucked up? I was inspired and excited about the possibilities for our future. And I was a woman in search of answers. (p. 171, *Louder than Words*).

It was my dedication to asking questions and researching—WHY his immune system was damaged, WHAT happened as a result, and HOW we can fix it that led us down the road to recovery. (p. 177, *Louder than Words*).

After evaluation was done she said to me "This isn't autism anymore. I don't understand what happened. We have never seen a recovery like this. What happened?" I replied, "I found a reason for autism, which led me to the solution, and because of that, he was able to absorb the lessons therapists were giving him." (p. 186, *Louder than Words*).

So I researched it and found that hyperbaric oxygen has been used for years for wound healing, to suppress inflammation and to help with autoimmune diseases like rheumatoid arthritis and lupus. I have lupus, so I thought this is a connection, this is yet another piece of the puzzle. (p. 70, *Mother Warriors*).

I spent hours online reading, researching, and e-mailing other parents I found asking for help and to share what they were doing for their kids, I went to the library and calculated how much mercury Maisie got in her shots, using the vaccine info from the doctor and the Physician's Desk Reference from the years those shots were made. (p. 81, *Mother Warriors*).

Our next plan of action was chelation (detoxing metals in the body). I was scared to try it at first, so I made sure I thoroughly researched it before we did it. Through extensive research and dozens of calls to pharmaceutical companies, I found out that Jeff had received at least 125 micrograms of mercury through thimerosal, the preservative in the vaccines injected into him. This made me sick to my stomach. (p. 95, *Mother Warriors*).

All I wanted to do was my own research because no one else would help me. So I got an Apple laptop. I always say this Apple laptop saved Zach's life because I was able to sit up until three, four in the morning in my bedroom without disturbing anyone. (p. 152, *Mother Warriors*).

Then I knew I was onto something. This was my sign to keep going. I went onto a Web site that I wound up falling in love with called talkingaboutcuringautism.org (p.154, *Mother Warriors*).

4.3.3 McCarthy's texts: Clusters recurring around the theme of Patient-physician relationships

In the era of postmodern medicine, the relationship between patients and healthcare providers is in the process of recalibration. This recalibration, ostensibly encouraged in both social science and medical literature, is an attempt to correct the compliance model of medicine, wherein doctor gives 'orders' and patients either in compliance or noncompliance. According to the literature, the compliance model structures an

inherently asymmetrical relationship between patients and their physicians, and discourages their active participation in the management of their own health. As such, there is been a trend away from compliance talk in the medical literature and toward a more egalitarian approach to patient-physician communication. To some, this egalitarian rhetoric is mere consumerist rhetoric that confounds “who is qualified to give medical advice and what the warrants are for taking it.” (Segal, 2005, p. 134).

In McCarthy’s texts, words which recur around the theme of patient-physician relationships are negative words that say little about what doctors do, and much about what doctors do *not* do: ‘the neurologist *never* showed up,’ ‘the medical community *doesn’t* understand,’ ‘doctor’s *don’t* do that’ ‘doctors *weren’t* telling moms,’ the pediatrician *didn’t* notice.’ Individuals doctors and the medical community at large is constructed as a passive and inert body, failing to inform parents of autistic children about the special diets, supplementation, chelation and other alternative therapies that parents claim ‘recover’ children from autism. Emphasis is placed on the incompetence and ineffectiveness of physician care (“I felt like we were in a Third World country, being cared for by thirteen year olds”) and there is an exasperated acknowledgement of physicians’ customary time constraints (“‘soon’ on hospital terms can mean ‘on the next shift change,’” “[doctors] say sorry and move you along,” etc.). The text from which these clusters were extracted follows.

But I learned that ‘soon’ on hospital terms can mean ‘on the next shift change.’ (p. 6, *Louder than Words*).

I wish I could say that the neurologist showed up that night, but he never did. They kept injecting him and injecting him and injecting him. This was supposed to be a well-respected hospital and I felt like we were in a Third World country, being cared for by thirteen year olds. (p. 23, *Louder than Words*).

I knew that the day before had been Easter, but I didn't want to believe that some asshole would rather stay seated at a dinner table with his ham and potatoes than come save my two year old. (p. 26, *Louder than Words*).

You would have thought his pediatrician might have noticed something along the way, mind you, but he did not. At one appointment he asked me if Evan was saying anything, and I said yes, because he was speaking a few words. That was the extent of my pediatrician checking for delays. (p.58, *Louder than Words*).

I wished to God the doctor had handed me a pamphlet that said "Hey sorry about the autism, but here's a step by step list on what to do next." But doctors don't do that. They say "sorry" and move you along. (p. 74, *Louder than Words*).

Well, no one ever told me. I never got the sorry-your-kid-has-autism-here's-what-to-do-next pamphlet." (p. 95, *Louder than Words*).

Even though this progress made me happy, I couldn't help but be pissed off that doctors weren't telling moms to at least try it. They really were against the diet. My thinking is that if the diet works on some autistic kids, that would link it to vaccines, and God forbid that happened. Doctors will never admit it, and it's a useless war to try and fight. (p. 107, *Louder than Words*).

As we talked about how the medical community doesn't understand that children with autism are actually physically sick and how pediatricians across the country have no idea how to fix them... almost every mom I know with a kid on the autism spectrum has gone to a pediatrician who has NO IDEA that certain symptoms exist in these kids...Pediatricians tell parents that we are overreacting, that all kids get constipated or that diarrhea is just part of autism...I was energized to lead the fight against pediatricians. (p. 27-28, *Mother Warriors*).

In additional to emphasizing all the things that pediatricians and health care professionals do not know (e.g. alternative treatments for autism) or do not do efficiently (e.g. showing up on time) McCarthy calls for the personalization of medicine based on parental research and preferences. Here, the recurrent cluster is *one-size-fits-all*. McCarthy rejects the practice of uniform medical treatment, and describes how she "made up her own rules" by requesting treatments she "felt were safe and necessary." The underlying point here is that McCarthy rejects the notion that children's bodies are the same or similar, and thus respond the same or similarly to vaccines or other medical treatments. She does not call for the suspension of vaccination, but rather argues that the government is obligated to offer a pre-vaccine test, which takes into account the

“individual child’s needs and biological makeup” and ensures that the individual child can “handle” the vaccines. The text from which these clusters were extracted follows.

Many people say that there are a lot of doctors taking advantage of hopeful moms by having them do too many treatments on their kid. I tend to agree, which was why I made up my own rules. This doctor wanted me to immediately start chelation, whereas I felt it was important to get Evan’s immune system functioning before I did something so harsh to his body. I planned to introduce one new treatment at a time and to test only the things I felt were safe and logical. (p. 139, *Louder than Words*).

Why would vaccine companies believe that vaccines could be safe for *all* children? It’s crazy to me. Let’s just say a child is born with an allergy to honey, and after a mom gives birth, the doctors rub honey all over this child’s body for the next eighteen months. Some bad shit is gonna happen. Then you tell the doctor “I think my child is allergic to the honey, because all his reactions point to honey.” The doctors ignore you and you think, “Hey maybe there should be a test to see if some kids are allergic to honey, so other moms don’t have to go through this anymore. (p. 174, *Louder than Words*).

The government can keep giving their vaccines, just give us the test to make sure our babies can handle them. If Evan had been tested for immunity or some sort of enzyme that was vulnerable to vaccines, none of this would have happened. Like I said before, I’m all for having vaccines in today’s world; I just believe that the government is obligated to offer a test to help moms know which child can take them—and which child can’t. (p. 175, *Louder than Words*).

I continued to speak about how the Centers for Disease Control acts as if vaccines are one-size-fits-all, as if they should be administered at the same rate for all children without regard to the individual child’s needs and biological makeup. (p. 9, *Mother Warriors*).

Oprah smiled and said, “And ONE SIZE DOES NOT FIT ALL!” (p. 16, *Mother Warriors*).

Are we to believe that ALL thirty-six vaccinations given now are ALL safe with no side effects? Give me a break. Are we supposed to buy the fact that these shots are one-size-fits-all? Or that every child is born with a perfect immune system? Wake the hell up, America, and think hard about the logic in this. In the meantime, I hope mothers across America will join me in our fight to change this insane vaccine schedule and demand that they GREEN our vaccines. Take the crap out! Enough is enough. (p. 215, *Mother Warriors*).

4.3.4 Offit’s texts: Clusters recurring around the theme of the Weakening of the Biomedical Narrative

Much discussion about postmodern medicine centers upon the tension between the “official” biomedical narrative of illness, and the micro-narratives of patients that challenge it. Traditionally, it has been assumed that the patient’s individual and subjective narratives of health and illness are superfluous when compared to the biomedical narrative, which standardizes the bodies and experiences of patients. Here,

Paul Offit operates from the perspective that, in fact, the patient narratives of medical experience are privileged over the “official” biomedical narrative of medical science. Offit describes the *powerful anecdotes* of parents with autistic children, and marvels at the ability of such anecdotes to *trump* statistical evidence and peer-reviewed studies. Statistics and epidemiological studies are described as “less convincing,” than anecdotes and “not sticky.”

Offit considers arguing against a mother’s narrative to be a “nearly impossible task” and states that such narratives are “hard to fight with statistical data.” He includes the quote of a pediatrician who says that “accurate evidence and citations of studies” are not resonant with parents in the same way that “dramatized stories” are. In the last quote, Offit claims that one of the advantages of parent narratives, in the context of the autism-vaccine debate, is their transmutability. These parent narratives can be “continually reshaped” to “fit the style of the time.” In contrast, the statistical evidence and epidemiological studies that Offit wishes were more persuasive, are more rigid; in order to be reshaped, they must first be subjected to both the scientific method and bureaucratic processes of legitimation. The text from which these clusters were extracted follows.

...some parents refused to accept the outcomes of these studies, preferring to believe that dramatic stories of Parker Beck and Aaron Sokoloski instead. (p. xx, *False Prophets*.)

Hill and Knowlton also used personal testimonies to trump epidemiological studies. (p. 188, *Deadly Choices*).

For many parents, the association in time between their children’s receipt of vaccines and the appearance of autism is far more convincing than epidemiological studies. That’s because anecdotal experiences can be enormously powerful. (p. 210, *False Prophets*).

McCarthy trumped science with personal anecdote: “My science is Evan, and he’s at home. That’s my science.” Had any of these television hosts chosen to have autism experts on their show, these experts would have had to argue against a mother’s personal, emotional story with statistics showing she was wrong—a nearly impossible task. (p. xx, *False Prophets*.)

By quoting Samuel Johnson, Stuart-Smith had hit on the central issue of the trial: the power of anecdote... Unfortunately it's hard to fight anecdote with statistical data. (p. 37, *Deadly Choices*).

Anti-vaccine groups are well organized and passionate. They have used popular settings such as Oprah and Larry King Live to make strong emotional appeals and get parents to think twice about having their children vaccinated. People, logical or not, do not forget this kind of emotional prowess. On the other hand, our medical and scientific experts counter with accurate evidence and citations of studies, which do not resonate with many parents. Dispassionate messages are not sticky. Gut wrenching stories... are. It is time we change." (p. 124, *False Prophets*).

In many ways, Jenny McCarthy and Barbara Loe Fisher are similar. Both dramatize their personal stories in vivid and heart wrenching terms... both Fisher and McCarthy continually reshape their message to fit the style of the time. (p. 152, *Deadly Choices*).

In addition to parents' "powerful anecdotal experiences," Offit identifies another source of challenge to the biomedical narrative of illness: the US court of Federal Claims. In his chapter discussing the Omnibus Autism Proceeding (a class-action lawsuit brought against the Federal government, comprised of parents who believe their child's autism was caused by vaccines) Offit makes several references to *scientific truth* and *medical truth* in conjunction with the claim that judges and juries are not appropriate arbiters of such truths, and that courtrooms are not suitable venues for truth-deliberation. Not only are juries and judges inappropriate arbiters of medical and scientific truth, but so too are individual treating physicians in the context of the Omnibus Autism Proceedings: Offit expresses dismay with the court's ruling, which gave preference to the testimony of an autistic child's treating physician over the "weight of epidemiological and biological evidence" and "decades of collective clinical experience." The text from which these clusters were extracted follows.

Waxman believed that the question of whether vaccines caused autism was a scientific one, best answered in a scientific venue. But many people don't believe that. They believe that any issue should have its day in court—that judges and juries should be the final arbiters of scientific truth. (p. 154, *False Prophets*).

Juries have historically been poor judges of scientific and medical truths. (p. 157, *False Prophets*).

All three judges had one thing in common: none had a professional background in science or medicine... Although scientists had already rendered a verdict on whether MMR or thimerosal caused autism, these three judges would be the final arbiters of scientific truth. (p. 159, *False Prophets*).

During one of Dan Burton's hearings, a clinician named Kathy Pratt, who took care of autistic patients, was convinced that vaccines were the culprit "regardless of what the research tells us." Because science is the only discipline that enables one to distinguish myth from fact, Pratt's statement was particularly unsettling. (p. 207, *False Prophets*).

Although science is open-minded, the scientific method isn't terribly politically correct. To determine whether medicine works, scientists establish a hypothesis, formulate burdens of proof, and subject those burdens to statistical analysis. Over time, a truth emerges. Something is either true or it isn't. (p. 207, *False Prophets*).

[The court] ruled, "medical records and medical opinion testimony are favored in vaccine cases, as treating physicians are likely to be in the best position to determine whether a logical sequence of cause and effect show[s] that the vaccination was the reason for injury." This ruling meant that the treating physician could trump medical consensus, trump the weight of epidemiological and biological evidence, and trump decades of collective clinical experience. All could be cast aside by the opinion of one doctor. (p.87, *Deadly Choices*).

...lawyers aren't scientists; they're not seeking some scientific truth. (p. 87, *Deadly Choices*).

4.3.5 Offit's texts: Clusters recurring around the theme of Internet use for health-related purposes

Nearly all of Offit's references made to Internet use for health-related purposes occur in close proximity (if not direct causal relation) to negative consequences: children with pneumonia, skin infections and meningitis; fake drugs bought over the Internet; the posting of provaccinationists' personal information, and the administering of dangerous autism therapies to children. Offit is clearly wary of web-health, and believes that it has the potential to be a great manipulator of parents, rather than a liberator of parents from the paternalistic control of physicians. Here, he describes information on the Internet as "typically unfiltered" and often "misleading and unnecessarily frightening."

Offit clearly sees danger in the prospect of physicians' advice being subjugated to the multitude of information/opinions/advice offered on the Internet. He makes frequent references to empowerment, expertise and research. With regard to patient empowerment through the Internet, he states that it "comes with a price"—the implied price being poor medical decision-making. He furthermore argues that "research" and "website browsing"

are too often conflated with one another, and are in reality quite different; the former is achieved by reading original epidemiological studies, the latter consists of “typing the word autism into Google.” As a result, Offit argues that formerly held notions of expertise are being challenged: “everyone is an expert (or no one is.)” To Offit, the implications of this are clear: if the road to ‘expertise’ is unrestricted (via the Internet) then the voices of “real” experts become indistinguishable. The text from which these clusters were extracted follows below.

During the next ten years, I saw several children come into our hospital with pneumonia caused by whooping cough, or severe skin infections caused by chickenpox, or meningitis caused by [Hib], because their parents had chosen not to vaccinate them. I asked why they had made that choice, they said vaccines were too dangerous: the whooping cough vaccine caused brain damage, the chickenpox vaccine caused paralysis, and the Hib vaccine caused diabetes. They had gotten their information from reports on the television or the radio, from articles in newspapers and magazines, or most commonly, the Internet. (p. xxiv, *False Prophets*).

And many parents bought an oral form of secretin through the Internet later found to contain only glycerin and water. (p. 15, *False Prophets*).

Quoting a journalist who expressed disbelief in the autism-vaccine link: “The next thing I knew my name and contact details had been published on the Internet and circulated to these parents groups. They wanted to put my name and details out there so that there could be a direct assault on a person. They want people. They want names and faces. (p. xx, *False Prophets*).

Today, on the other hand, resistance to vaccines is found in the upper-middle class among parents who are college-and graduate-school-educated, likely to use the Internet to make healthcare decisions, and fully believing that they, too, can become experts in an information age. The problem, however, lies in how they obtain their expertise. Magazine and newspaper articles and the Internet often provide information that is misleading and unnecessarily frightening. And it’s not hard to find like-minded people on the Internet, no matter how small the group or how outlandish the belief. (p. 124, *Deadly Choices*).

Doctors are more apt to encourage patients to actively participate in their own medical care. And nothing has empowered people more than the Internet...But empowering parents to make medical decisions comes with a price. Information on the Internet is typically unfiltered—anyone can say anything—and health advice is terribly misleading. (p. 202, *False Prophets*).

“I’ve done my research,” parents will say, “and I don’t want my child to have that shot.” By “research” the parents usually mean that they have perused a variety of Web sites on the Internet. But that’s not research. If parents want to do genuine research on the subject of vaccines, they should read the original studies of measles, mumps and rubella vaccines; compare them with studies of the combined MMR vaccine; and analyze the ten epidemiological studies that examined whether MMR caused autism. If they want to research thimerosal, they should read the hundred or so studies on the mercury toxicity, as well as the eight epidemiological studies that examined whether thimerosal caused harm. (p. 202, *False Prophets*).

Because of the Internet, everyone is an expert (or no one is.) As a consequence, for some, there are no truths, only different experiences and different ways of looking at things. (p. 203, *False Prophets*).

For many parents, the advice given by health care professionals about vaccines is just one more opinion in a sea of opinions, offered on the Internet. (p. 205, *False Prophet*).

McCarthy had trumped her pediatrician's four years of medical school, three years of residency trained in pediatrics, and many years of experience practicing medicine by typing the word autism into Google. There she found a wealth of purported therapies her pediatrician didn't know about—therapies she believed had cured her son. She was amazed that an underground network of doctors—the only doctors who seemed to care about children with autism—was available at her fingertips. It was inconceivable to her that her pediatrician didn't know what she now knew. That the theories proposed by these doctors are varied or contradictory; that their therapies can be dangerous' that some of these doctors had been brought up before disciplinary committees for substandard medical practices and that her doctor, far from not knowing about them, was likely frightened by them was not something that McCarthy had considered possible. (p. 242, *False Prophets*).

4.3.6 Offit's texts: Clusters recurring around the theme of changing patient-physician relationships

Much has been made of the diversification, or commercialization, of the healthcare 'industry.' This commercialization is considered a major driving force behind the reconceptualization of the 'compliance' model in medical and social science literature, which has transformed 'patient-physician' relationships into 'client-provider' or 'consumer-provider' relationships. From the texts, it is evident that Offit considers this commercialization of health care to be the source of suspicion on the parts of patients/clients. *Conflicts of interest/financial investments* and the *fronting/hawking* of pharmaceutical products are recurrent threads in his discussion.

He points out that alternative treatments for autism, such a chelation, vitamin injections, etc., are expensive (since they are not covered by insurance) and thus, parents' financial investment helps solidify belief in their efficacy. Additionally, he suggests that parents may be motivated to believe in the vaccine-autism connection because, if it can be proven in vaccine court, they will be entitled to generous compensation. Additionally,

Offit identifies the growth of Direct-to-consumer advertising as a reason why patients might be suspicious of the medical community as a whole, as they are constantly subjected to the ‘hawking’ and ‘fronting’ of impotency, allergy and other lifestyle pharmaceuticals by companies that are increasingly beginning to look like “snakeoil salesmen.” He points out that no one in this debate is without financial conflicts of interest: McCarthy herself promotes pharmaceutical products for the treatment of autism, and the parent-advocates, politicians and scientists who speak out against vaccines are “rarely without” similar conflicts of interest. This contributes to an environment wherein it is only reasonable to be skeptical of the motivations of any and all participants in the autism-vaccine debate, as nearly all parties appear to have a financial stake in the matter.

The text from which these clusters were extracted follows.

Such difficult behaviors have driven some parents to seek extreme medical therapies. Unfortunately, doctors have been all too willing to comply. (p. 5, *False Prophets*).

Many parents of children with autism are tired of the glacial pace of medical research, tired of slogging through hours of behavioral therapy, and tired of watching children improve at a rate so slow it’s hard to tell if they are improving at all. They want something now, something that will immediately release them from the prison of autism. (p. 6, *False Prophets*).

Wakefield knew that parents of children in his study had a financial interest in finding a link between MMR and autism; if Wakefield could establish that link, these parents could successfully sue for compensation. (p. 38, *False Prophets*).

Parents not only had an emotional investment in the idea that secretin works, they also had a financial investment, some having spent thousands of dollars to obtain the drug... (p. 124, *False Prophets*).

David Kirby, Dan Burton, Robert F. Kennedy Jr., personal-injury lawyers, and parents were angry and frustrated. They wanted someone to pay for the vitamin injections, blood tests, anti-fungals, anti-virals, mineral supplements, cranial manipulation, special diets, sonar depuration, hyperbaric oxygen, Lupron, and chelation. So they turned to two groups who had those resources: pharmaceutical companies and the federal government. (p. 155, *False Prophets*).

Although those who claim that vaccines cause autism have been quick to point out conflicts of interest among scientists and doctors who disagree with them, few of the parent advocates, politicians, or scientists who speak against vaccines are without conflicts. (p. 199, *False Prophets*).

Although McCarthy and Fisher openly despise pharmaceutical companies, McCarthy promotes their products. (p. 153, *False Prophets*).

According to McCarthy's logic, then, those who promote vaccines are evil because they're fronting for products that gross \$17 billion a year; while those who promote supplements are virtuous because they're fronting for products—almost all of which are of unproved efficacy—that gross \$80 billion a year. (p. xx, *Deadly Choices*).

It's hard to argue the special place of an industry in society when it's hawking yet another impotency product. Companies are starting to look like snakeoil salesmen. (p. 199, *Deadly Choices*).

In addition to the climate of suspicion that the commercialization of health care has fomented, it has also encouraged parents to view vaccination as an individual, personal choice rather than a collective responsibility. *Immunological cooperative* and *trust* are recurrent and interconnected clusters in Offit's discussion of the current context of health care. He discusses the individual, customizable vaccination schedule proffered by “rogue” doctor, Robert Sears, at length as proof of this trend toward framing vaccination as an individual choice. To recover the communal framing of vaccination, Offit makes a call for patients to identify with those who are directly involved with the research, production and promotion of vaccines. According to Offit, if we understand that the CDC, AAP, etc. are “just like us,” with children “just like ours,” then we can trust them, follow their recommended schedule, and once again be united as an immunological cooperative, rather than a heterogeneous amalgam of parents with different concerns, and preferences, and entitled to individual choice. The text from which these clusters were extracted follows.

For parents looking for a way to delay, withhold or separate or space out vaccines, Dr. Bob's schedule is the way to go; many parents bring it to their doctor's office and say “this is the one I want.” (p. xx, *Deadly Choices*).

Sears, like Regan before him, is appealing to a generation that doesn't consider a larger cooperative—an immunological commons... Now that herd immunity has broken down, Sears' position that one should think only of oneself no longer works. (p. 184-185, *Deadly Choices*).

And parents trust him. Oddly, they trust him because he doesn't have an expertise in vaccine science—an expertise that would likely have inspired the DCD, AAP, FDA, professional medical organizations or vaccine makers to seek his advice. (p. 187, *Deadly Choices*).

Eventually, we are going to have to appreciate the CDC officials aren't against us—they are us. Those involved with vaccines include doctors and scientists who are also parents, aunts, uncles and grandparents. (p. xx, *Deadly Choices*).

The implication is clear—any association with vaccine makers is unacceptable. The media buy it; congressional committees buy it; parents buy it. And once bought, the implication effectively eliminates a lot of expertise from the debate—leaving people like Robert Sears, a man with no published experience on vaccine science or safety, to do a lot of the talking. (p. 202, *Deadly Choices*).

If we are to get past the constant barrage of misinformation based on mistrust, we have to set aside our cynicism about those who test, license, recommend, produce and promote vaccines. (p. 206, *Deadly Choices*).

Following the tragedy of September 11, 2001, there was a moment when we all stood still and looked at each other. No longer individuals, we were part of a whole. Personal interests were irrelevant. We were united in our grief. One. Then the moment was gone, dissolved into a cloud of lawsuits, finger pointing, partisanship and blame. But, although fleeting, it had been there. And if we can recapture it—recapture the feeling that we are all in this together, all part of a larger immunological cooperative—the growing tragedy of children dying needlessly from preventable infections can be avoided. (p. 214, *Deadly Choices*).

5. DISCUSSION AND CONCLUSION

Many of the discursive threads pertaining to the autism-vaccine controversy underline that which Frank (1996) identifies as the key defining feature of postmodern medicine: “...people feeling a need for a voice they can recognize as their own.” (p. 7). This growing interest in, or expectation of, having a voice with which to articulate one’s own experience(s) of health and illness is tightly connected to two of the additional themes of postmodern medicine, specifically, the use of the internet for health-related purposes as well as the evolved and evolving nature of patient-physician (i.e. client-provider) relationships. Despite patients’ heightened interest in and expanded technological means for exercising “voice” in their own micro-narratives of illness, the opportunity for individual patient voices to be registered in the traditional clinical encounter has not expanded accordingly. The continued (and perhaps intensified) circumscription of patient agency in clinical encounters can be attributed, at least in part, to the growing number of administrative duties that impose constraints on how physicians’ time is spent. According to Braddock & Snyder (2005), these constraints “may cause the physician to overlook or pay insufficient attention to patients’ psychosocial concerns” and encourages an efficiency that potentially reproduces and reinforces the traditional asymmetrical power balance inherent in traditional patient-physician relationships, wherein the physician is “overly controlling of the visit and the conversation (with frequent interruption when the patient speaks.)” (p. 4-5). McCarthy’s experience of patienthood aligns with studies such as the above: in her texts are multiple references to feeling ignored, dismissed or “made to feel stupid” in clinical encounters with physicians. It is not unreasonable to suppose that patients’ perception of physician negligence or dismissal likely stem from

physicians' administratively-imposed need to maximize efficiency by imparting (only) the necessary information to a patient before moving on to the next. This sort of administrative efficiency can easily be interpreted by a patient as controlling or dismissive.

With regard to specific clinical encounters wherein vaccines are administered, McCarthy points out that "Some moms worry they didn't scream loudly enough when they had concerns about vaccination." These unaddressed concerns are asserted by McCarthy to be the product of maternal instinct (elsewhere referred to as 'emotional guidance system or 'mommy radar'). While the emergence of the theme "maternal instinct" might not seem like an overly consequential point within the debate, "instinct" is a term that figures prominently throughout the autism-vaccine controversy, as well as antivaccination discourses more broadly. High-profile medical professionals within the vaccine debate have discussed the role of parental/maternal instinct, including Andrew Wakefield himself who asserts that, with regards to the vaccine-autism link, "we must listen to the parents." (Deer, 2004). This is a potentially effective rhetorical strategy on two counts. First, the notion of a unique mothering instinct is deeply embedded within Western society, as far back as 1781 when Darwin argued in *Descent of Man* that the instinct of motherhood is the greatest in nature. To argue against the existence of this intuitive form of knowledge is to argue against hundreds of years of scientific and popular lore. Secondly, there is no way to logically disprove a maternal instinct. Since instinctual knowledge is intuitive and not rooted in logic per se, it is arguably impervious to logical argument or scientific data. That is to say, an instinct cannot be right or wrong, an instinct simply *is*. When parents claim to know, by way of instinct, some essential

detail about their child's wellbeing, the claim is difficult to argue against or disprove because of the esteem granted to "maternal instinct" in the public imagination, and because of its imperviousness to forms of counterargument.

The feeling of one's voice being marginalized in the postmodern medical context is a feeling that ostensibly cuts both directions, that is to say, a feeling common to both patients *and* physicians. Whereas patients like McCarthy consider the clinical encounter to be a space wherein the patient's voice is marginalized, Offit considers spaces *outside* the clinical encounter to be spaces wherein the expert's voice is marginalized and "scientific truth" is more susceptible than ever to being muffled or muzzled. For Offit, scientific truth is the product of empirical and statistical forms of evidence that garner large-scale consensus within expert communities. He makes repeated mention of the ability of patients' micro-narratives (as well as those of "rogue" physicians) to *trump* epidemiological studies and the scientific truth they help produce. He repeatedly mentions the emotional power inherent in the narratives and anecdotes of parents, and says that arguing against these narratives is "a nearly impossible task" because "dispassionate [expert] messages are not sticky." (p. 124). Furthermore, as Offit contends, personal narratives and anecdotes of illness are fluid and can more easily be reshaped to fit the rhetor's needs in a given rhetorical moment, whereas epidemiological studies take years, not to mention institutional backing and financial resources, to complete and thus lack the transmutability that patient narratives enjoy.

Offit posits that parents themselves, as well as the actors within the judicial system who assess the truth-value of legal claims, are not effective or appropriate arbiters of medical and scientific truths. Offit likewise does not consider individual treating

physicians to be effective arbiters of medical truths. He expresses dismay several times throughout the texts that, in the case of the Autism Omnibus Proceedings, the “opinion” of a child’s treating physicians is able to “trump” epidemiological evidence or medical consensus. In Offit’s view, medical and scientific truths related to autism etiology can only be discovered, represented and defended through the lens of large-scale epidemiological studies and statistical evidence that garner expert consensus.

However, if statistical evidence garnered from large-scale studies is to be considered the best or perhaps only appropriate means through which truths about the body can become known, opportunities for patients to exercise rhetorical agency in the narrative construction of their illnesses are highly constrained. Not only do laypublics lack the technical and institutional resources needed to participate in the conducting of such research, but the high-context and jargonistic language of medical research makes it largely inaccessible to those outside the expert community. Cleary McCarthy and other parents of autistic children have no interest in playing a traditionally circumscribed role (for which Offit implicitly advocates) in the understanding of their own bodies or the bodies of the family members for whom they take care. As Frank (1996) points out, when postmodern patients lack opportunities (in medical contexts) to participate in crafting “stories” of illness, they find other outlets through which to do so.

As evidenced in McCarthy’s and Offit’s texts, the primary means for disillusioned or voiceless patients to recover voice is through the Internet—much to McCarthy’s relief and to Offit’s chagrin. While biotechnologies like genetic testing, prosthetics and the like have radically altered the biomedical conception of bodies as mechanistic or static, the Internet has altered the biomedical model of health communication in ways that are

equally dramatic. For McCarthy, the Internet is both a means for accessing medical information, piecing it together (in narrative form) in ways that relate to one's own body, and relaying it to other Internet users. In the case of an unknown or parentally-contested medical diagnosis, (which applies to McCarthy's son who was initially given a diagnosis of epilepsy) the Internet can be a vehicle for patients to seek out information on their own accord, outside of the clinic and outside of their treating physician's contact hours. This opportunity appears to be increasingly desirable for patients: according to a 2011 Pew research survey, over 80 percent of Internet users have sought health-related information online. ("The social life of health information, 2011"). In the case of McCarthy and the other mothers quoted in her text, the Internet proved to be an invaluable tool for reducing uncertainty about the etiology and prognosis of autism. Because the etiology and prognosis of autism have yet to be scientifically solidified in the way that, say, diabetes has, McCarthy unsurprisingly relied on information outside of the medical mainstream in order to further investigate the cause(s) of and solution(s) for her son's autism. This information consisted largely of alternative medicine websites like taca.org ("Talking About Curing Autism") as well as the personal blogs maintained by the parents of autistic children. Such websites tend to emphasize the *unique* nature of autism etiolog-y(ies) and workable solutions for individual cases of autism. Possible etiologies, as suggested on taca.org and cited by the "mother warriors" in McCarthy's texts include (first and foremost) compulsory vaccination, environmental and food toxins, as well as household chemicals (mold, cleaning products, etc.). Suggested solutions include diet, vitamin supplementation, oxygen therapy and mercury chelation. McCarthy and other mothers advocate the Internet as the primary tool for "piecing together the puzzle" of their child's

unique case of autism. After determining the “cause” of a child’s autism, McCarthy suggests, parents can sleuth for the unique combination of alternative treatments that is capable of “leading [their children] down the road of recovery.” (It goes without saying that most of these alternative treatments are available for purchase over the Internet.) In this way, the Internet—referred to by McCarthy most often as “the University of Google”—is understood to be a neutral, value-free tool that exists outside the dogmatic and corrupt interests of the medical community, and is capable of leading parents to valuable medical information untainted by the political and economic interests that motivate the information gatekeepers of the mainstream medical community. After seeking out such information, McCarthy and other parents are able to “pay it forward” by relaying their experiences of autism’s unique causes and solutions to other confused and hopeful parents. In this way, the production of medical knowledge *becomes a matter of shared or collective responsibility* (whereas medical decision-making is a matter of individual preference and choice).

Medical professionals like Offit are highly skeptical, hostile even, to the notion that the Internet is capable of enabling laypublics to gain medical expertise. Nearly every mention of the Internet within Offit’s texts is linked with a negative scenario or serious consequence (e.g. the spread of misinformation, the sale of fraudulent health-related products and the intentional disclosure of provaccinationists’ personal information). It is apparent that from Offit’s vantage, the Internet represents a force capable of undermining (or “trumping”) expert consensus on health-related matters, and thus, capable of disrupting public health. While the Internet may offer a wealth of health-related resources like WebMD.com, Emedicine.net and countless other sites dedicated to the dissemination and

discussion of health information, Offit and other medical professionals are quick to distinguish between “Internet searching” and “medical researching.” The differentiation between the two rests on the function of gatekeepers. In Offit’s view, engaging in true “medical research” requires that the information sources have been filtered through peer-review and editing processes before dissemination. He suggests that parents wishing to conduct true “medical research” ought to pursue peer-reviewed journal articles, leaving unacknowledged the fact that access to this type of information tends to be restricted; these articles are often guarded by an online paywall or require a journal subscription. Furthermore, as mentioned earlier, the highly technical and restrictive language of peer-reviewed journals is likewise not accessible to nonscientific publics. Information found on the popular health-oriented websites mentioned above, however, tends to be written in more accessible language, which some worry “dilutes” the content and allows for misinterpretations that stoke patient anxieties.⁸ Additionally, Offit voices concern about the participatory features of health-information on the web: medical commentary on forums tend to be unfiltered, and as a result, it is “not hard to find like-minded people...no matter how small the group or how outlandish the belief.” (p. 124). In other words, “fringe” health beliefs, unsupported by scientific and medical consensus, can easily gain popularity and morph into mainstreamed, centralized beliefs. Because of this, Offit views the collective production of web-based health knowledge as a grave liability, rather than a potentiality for patient empowerment. In Offit’s view, true patient empowerment does not mean merely having access to a voluminous body of medically-oriented information. Rather, patient empowerment rests on the ability of patients to

⁸ See White, R. & Horvitz, E. (2009). "Cyberchondria: Studies of the escalation of medical concerns in Web search". *ACM Transactions on Information Systems* 27 (4), 1.

access scientifically supported medical information and to interface with medical experts who interpret said medical information in conjunction with patients but, mostly, *on patients' behalf*.

In practical terms, the problem with this conception of patient empowerment is it presupposes fairly extensive interfacing between patients and their physicians. As discussed earlier, this extensive interfacing is not often a possibility given physicians' growing time constraints. An additional challenge to this view of patient empowerment, as evidenced by both McCarthy's and Offit's texts, is the clear bi-directional lack of trust between the two parties: McCarthy does not trust organizations like the American Academy of Pediatrics or the Centers for Disease Control (and the "physician-drones" who parrot their dictates) when they assert that vaccinations are a medically necessary form of (preventative) treatment; likewise, Offit does not trust in the capacity of parents to conduct "legitimate" medical research before making medical decisions or to assume a sense of "collective responsibility" for helping to secure public health. He also questions the financial motives of parents within the antivaccination movement. For example he is very suspicious of McCarthy's endorsement of preferred alternative medical therapy products such as particular brands of vitamins; he also questions the extent to which potential financial gains persuade litigious parents into believing that vaccination caused their child's autism.

It seems apparent that this bi-directional lack of trust has been fomented by the intensified commercialization of medicine. Though the reshaping of patient-physician relationships has served to ameliorate some long-standing relational problems like excessive paternalism, (Friedson, 1970) new (and perhaps more complicated) relational

problems have been simultaneously created. As described earlier, the traditional model of patient “compliance,” which structured a highly asymmetrical power relationship between physicians and patients, has been challenged by a number of scholars, bioethicists and physicians themselves. Cuthbertson & Noble (1997), writing in the *British Medical Journal*, have even gone so far as to suggest that the “medical beliefs and opinions” held by doctors and patients ought to be considered “equally valid.” Since then, the compliance model has given way toward more egalitarian approaches to health care, wherein the patient is enjoined to exercise a greater degree of agency in medical decision-making than ever before. The trends in pharmaceutical advertising reflect and reinforce patients’ increased role in medical decision-making: pharmaceutical companies now spend nearly equal amounts of money advertising to consumers as they do physicians (“Marketing and Direct-to-Consumer Advertising (DTCA) of Pharmaceuticals”, 2010).

This rhetoric of egalitarian health care, however appealing, is not without its detractors. For example, Segal (2009) argues that egalitarian models of participative health care amount to “consumerist rhetoric and...a rhetoric of rights that may be totally inappropriate to questions of health and illness.” (p. 143). Given the “rhetoric of rights” that the consumer-driven logic of medicine has summoned into being, it is not surprising that McCarthy and other parents react against the *compulsory* vaccination of their children. As is emphatically repeated throughout McCarthy’s texts, one of her primary objections to the current vaccination schedule is that it presupposes that “one-size-fits-all.” Compulsory one-size-fits-all medical treatments are not only incompatible with the consumer-driven logic of egalitarian health care, they also harken back the weakened (but extant) biomedical paradigm of medicine wherein bodies were conceived as an

interchangeable and mechanistic sum of parts (Frank, 1996; Morris, 1998). The conception of the body as mere totality of interchangeable parts is one that postmodern patients are increasingly reluctant to accept; the booming industry of personalized medicine (wherein decisions and practices are customized to the individual patient's genetic code, lifestyle preferences, etc.) attests to this. In fact, McCarthy herself, as well as the other mothers quoted in her text, do not call for an abolishment of all vaccination programs, rather, they are requesting that physicians offer flexible vaccination schedules that are tailored to the individual child, as well as pre-vaccination tests that would indicate whether a child's unique physiology is likely to interact negatively with the vaccine.

In sum, the threads of a burgeoning postmodern medicine, identified here as the weakening of the biomedical narrative, the use of the Internet for health-related purposes, and the commercialization of patient-physician (a.k.a client-provider) relationships, are deeply interconnected and mutually reinforcing. That is to say, the growing reluctance of patients to accept the "official" biomedical narrative of health and illness is enabled and reinforced by the expanding technological means for sharing micro-narratives of health and illness and seeking "alternative" medical information; in utilizing these technologies, patients are exposed to a range of voices (e.g. DTC advertising) that presuppose and strengthen their increased agentive role in decision-making, which in turn shapes patients' expectations for greater agency in clinical contexts. When these expectations are not met in the traditional clinical encounter (as is often the case, according to Braddock & Snyder, 2005) patients like McCarthy can become dissatisfied and distrustful of their treating physicians. Physicians, likewise, become distrustful of patients whom they view

as liable to circumvent and undermine their treating physicians' counsel by seeking and sharing "fringe" medical beliefs that can become "central" if critical mass (and the right alignment of interested parties) is reached.

The autism-vaccine controversy stands in the intersection of these threads, and thus, is an instructive case study in the complexities and challenges of health communication in the era of postmodern medicine. As this particular controversy illustrates well, the health communication challenges that occur at the micro-level of individual patient-physician encounters can easily ripple out and manifest themselves in the macro-level of public health, and vice versa. An especially salient concern vis-à-vis public health is that, in the context of postmodern medicine, patients are likely to view the production and dissemination of medically-oriented information as a matter of *collective responsibility*, while medical decisions-making is likely to be viewed as a matter of *individual choice or preference*. In a world where global travel is becoming increasingly commonplace, the need to effectively navigate these tendencies, in ways that are beneficial to both the individual and the collective, becomes all the more acute. This need seems unlikely to be met without a thorough understanding of the uniquely postmodern contours and characteristics that comprise the emergent era of medicine in which we find ourselves; it is to this end that this project has sought to contribute.

CITED LITERATURE

- Abbott, V. (2000). Web page quality: Can we measure it and what do we find? A report of exploratory findings. *Journal of Public Health*, 22(2), 191-197.
- Adams, S. (2010). New resource for autism coverage. *The ASHA Leader*, 15(11), 46.
- Allen, A. (2007). *Vaccine: the controversial story of medicine's greatest lifesaver*. New York: W.W. Norton.
- Autism spectrum disorders (ASDs) (n.d.). *Centers for Disease Control and Prevention*. Retrieved March 27, 2011, from <http://www.cdc.gov/ncbddd/autism/index.html>
- Baker, J. P. (2008). Mercury, vaccines and autism: One controversy, three histories. *American Journal of Public Health*, 98(2), 224-253.
- Bakir, F., Damluji, S., & Amin-Zaki, L. (1973). Methylmercury poisoning in Iraq. *Science*, 181, 230-241.
- Ball, L., Evans, G., & Bostrum, A. (1998). Risky business: Challenges in vaccine risk communication. *Pediatrics*, 98(2), 453-458.
- Beck, U. (1992). *The risk society*. London: Sage.
- Berndt, E. R., Denoncourt, R. N., & Warner, A. C. (2009). *U.S. markets for vaccines: Characteristics, case studies, and controversies*. Washington, D.C.: AEI Press.
- Best, S., & Kellner, D. (1991). *Postmodern theory: Critical interrogations*. New York: Guilford Press.
- Bettelheim, B. (1967). *The empty fortress; infantile autism and the birth of the self*. New York: Free Press.
- Boyce, T. (2006). Journalism and expertise. *Journalism Studies*, 7(6), 889-906.
- Boykoff, M., & Boykoff, J. (2004). Balance as bias: Global warming and the U.S. prestige press. *Global Environmental Change*, 14, 125-136.
- Braddock, C. & Snyder, L. (2005). Ethics and time, time perception, and the physician-patient relationships. *American College of Physicians*: position paper.
- Bucchi, M. (1998). *Science and the media: alternative routes in scientific communication*. New York: Routledge.
- Burke, K. (1941). *The philosophy of literary form: studies in symbolic action*. Baton Rouge: Louisiana State University Press.

- Burke, K. (1950). *A rhetoric of motives*. New York: Prentice-Hall.
- Campbell, D. (2007, July 8). I told the truth all along, says doctor at heart of autism row. *The Observer*. Retrieved April 14, 2011, from <http://www.guardian.co.uk/society/2007/jul/08/health.medicineandhealth1>
- Clarke, C. (2008). A question of balance: The autism-vaccine controversy in the British and American elite press. *Science Communication*, 30(1), 77-207.
- Coburn, D. (2006). Medical dominance then and now: critical reflections. *Health Sociology Review*, 15(5), 432-443.
- Colgrove, J., & Bayer, R. (2005). Could it happen here? Vaccine risk controversies and the specter of derailment. *Health Affairs*, 24, 729-739.
- Cuthbertson, B., & Noble, D. (1997). Compliance: A broken concept. *British Medical Journal*, 314" 690-691.
- Data and statistics. (n.d.). *World Health Organization*. Retrieved May 23, 2011, from www.who.int/research/en/
- Davies, P., Chapman, S., & Leask, J. (2002). Antivaccination activists on the world wide web. *Archives of Disease in Childhood*, 87: 22-25.
- Davis, M. S., & Eichorn, R. L. (1963). Compliance with medical regimens: A panel study. *Journal of Health and Human Behavior*, 4(4), 240-249.
- Dearing, J. W. (1995). Newspaper coverage of maverick science: Creating controversy through balancing. *Public Understanding of Science*, 4(4), 341-361.
- Deer, B. (2004, February 22). Revealed: MMR research scandal. *The Times*. Retrieved April 14, 2011, from http://www.timesonline.co.uk/tol/life_and_style/health/article1027636.ece
- Durbach, N. (2005). *Bodily matters: the anti-vaccination movement in England, 1853-1907*. Durham: Duke University Press.
- Entman, R. M. (1993). Framing: Towards clarification of a fractured paradigm. *Journal of Communication*, 43(4), 51-58.
- Foss, S. K. (2009). *Rhetorical criticism: exploration and practice* (4th ed.). Long Grove, Ill.: Waveland Press.
- Foucault, M., & Sheridan, A. M. (1973). *The birth of the clinic: an archaeology of medical perception*. London: Tavistock.

- Fox, S. (2011, May 12). The social life of health information, 2011 . *Pew Research Center's Internet & American Life Project*. Retrieved June 27, 2011, from <http://www.pewinternet.org/Reports/2011/Social-Life-of-Health-Info.aspx>
- Frank, A. W. (1995). *The wounded storyteller: body, illness, and ethics*. Chicago: University of Chicago Press.
- Freidson, E. (1970). *Profession of medicine; a study of the sociology of applied knowledge*. New York: Dodd, Mead.
- Friedman, H. S., & DiMatteo, M. R. (1982). The social influence of physicians and health care practitioners as agents of change. *Interpersonal issues in health care* (pp. 33-50). New York: Academic Press.
- Giddens, A. (1987). *Social theory and modern sociology*. Stanford, Calif.: Stanford University Press.
- Godlee., & Marcovitch. (2011). Wakefield's article linking MMR vaccine and autism was fraudulent. *British Medical Journal*, 342, 1678.
- Gross, L. (2009). A broken trust: lessons from the vaccine-autism wars. *PLoS Biology*, 7(5): e1000114. doi:10.1371/journal.pbio.1000114
- Harter, L. M., Japp, P. M., & Beck, C. S. (2005). *Narratives, health, and healing: communication theory, research, and practice*. Mahwah, N.J.: Lawrence Erlbaum Associates, Publishers.
- Hillier, D. (2006). *Communicating health risks to the public: a global perspective*. Aldershot, England: Gower.
- Hodgkin, P. (1996). Medicine, postmodernism and the end of certainty. *British Medical Journal*, 313, 1568-1569.
- Holm, S. (1993). What is wrong with compliance? . *Journal of Medical Ethics*, 19, 108-110.
- Hughes, J. (n.d.). Tomoko Uemura, R.I.P. . *The Digital Journalist*. Retrieved June 27, 2011, from <http://digitaljournalist.org/issue0007/hughes.htm>
- Jackson, R., & Huffman, D. (1990). Patient compliance: the financial impact on your practice. *The NARD Journal*, 1(1), 67-71.
- Jenkins-Smith, H. Silva, C. & Song G. (2010). *Health policy survey 2010: A national survey on public perceptions of vaccination risks and policy preferences*. Center for Risk and Crisis Management, University of Oklahoma, Norman, OK.

- Kanner, L. (1943). Autistic disturbances of affective content. *Nervous Child*, 2, 217-250.
- Kaufman, S.R. (2007). An event in the history of thought: autism and vaccine safety doubt. *Proceedings of the American anthropological association conference*. Washington, DC.
- Kivits, J. (2006). Informed patients and the Internet: A mediated context for consultations with health professionals. *Journal of Health Psychology*, 11(2), 269-282.
- Leach, M., & Fairhead, J. (2007). *Vaccine anxieties: global science, child health and society*. London: Earthscan.
- Lingoes, C. (1993). Expert knowledge and decision-making in controversy contexts. *Public Understanding of Science*, 2, 417-426.
- Lyotard, J. (1984). *The postmodern condition: a report on knowledge*. Minneapolis: University of Minnesota Press. (Original work published 1979).
- Marketing and advertising of pharmaceuticals. (2010, November 1). *National Conference of State Legislatures*. Retrieved June 27, 2011, from <http://www.ncsl.org/default.aspx?tabid=14461>
- Martins, D. S. (2005). Compliance rhetoric and the impoverishment of context. *Communication Theory*, 15(1), 59-77.
- Measles --- United States, January--May 20, 2011. (n.d.). *Centers for Disease Control and Prevention*. Retrieved June 27, 2011, from http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6020a7.htm?s_cid=mm6020a7_w
- Miles, A., Loughlin, M., Polychronis, A. Evidence-based medicine, clinical knowledge and the rise of personalized medicine. (2008). *Journal of Evaluation in Clinical Practice*. 14: 621-639.
- Morris, D. B. (1998). *Illness and culture in the postmodern age*. Berkeley: University of California Press.
- Poland, G. A., Jacobson, R. M., & Osyannikova, I. G. (2009). Trends affecting the future of vaccine development and delivery: The role of demographics, regulatory science, the antivaccine movement and vaccinomics. *Vaccine*, 27(25-26), 3240-3244.
- Powell, H., & Jameison, W. (1937). On the efficacy of 'Merthiolate' as a biological preservative after ten years' use. *Proceedings of the Indian Academy of Science*, 47, 65-70.
- Risk communication. (n.d.). *World Health Organization*. Retrieved May 20, 2011, from

<http://www.who.int/foodsafety/micro/riskcommunication/en/>

- Rains, S. A. (2008). Health at high speed: Broadband Internet access, health communication, and the digital divide. *Communication Research*, 35 (3): 283-297.
- Roberts, A. C. (2000). *Fredric Jameson*. London: Routledge.
- Segal, J. (2005). *Health and the rhetoric of medicine*. Carbondale: Southern Illinois University Press.
- Segal, J. Z. (2009). Internet health and the 21st century patient: a rhetorical view. *Written Communication*, 26(4), 351-369.
- Shildrick, M. (1997). *Leaky bodies and boundaries: feminism, postmodernism and (bio)ethics*. London: Routledge.
- Sim, S. (2002). *Irony and crisis: a critical history of postmodern culture*. Cambridge: Icon.
- Spallone, P., & Steinberg, D. L. (1987). Do we need all this? . *Made to order: the myth of reproductive and genetic progress* (p. x). Oxford: Pergamon Press.
- Stobbe, M. (2007, January 6). Will autism fraud report be a vaccine booster?. *PhysOrg.com - Science News, Technology, Physics, Nanotechnology, Space Science, Earth Science, Medicine*. Retrieved June 27, 2011, from <http://www.physorg.com/news/2011-01-autism-fraud-vaccine-booster.html>
- Thimerosal in Vaccines. (n.d.). *U S Food and Drug Administration*. Retrieved April 16, 2011, from <http://www.fda.gov/BiologicsBloodVaccines/SafetyAvailability/VaccineSafety/UCM096228>
- Webster, F. *Theories of the information society*. London and New York: Routledge, 1995.
- Wertheimer, A., & Santella, T. (2003). Medication compliance research: Still so far to go. *Journal of Applied Research In Clinical and Experimental Therapeutics*, 3(3), 254-291.
- White, R., & Horvitz, E. (2008, November 1). Cyberchondria: Studies of the escalation of medical concerns in web search - Microsoft Research. *Microsoft Research*. Retrieved June 27, 2011, from <http://research.microsoft.com/apps/pubs/default.aspx?id=76529>
- Wolfe, R. M., Sharp, L. K., & Lipsky, M. S. (2002). Content and design attributes of

antivaccination web sites. *Journal of American Medical Association*, 287(24), 3245-3248.

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