**Examining the Social Construction of Health, Illness, and
Wellness in Anti-Science Communities**

by

Meredith Mattlin

Thesis

Submitted to the Faculty of the

Graduate School of Vanderbilt University

in partial fulfillment of the requirements

for the degree of

MASTER OF ARTS

in

Medicine, Health & Society

May 11, 2018

Nashville, Tennessee

Approved:

Laura Stark, Ph.D.

JuLeigh Petty, Ph.D.

INTRODUCTION

Science and medicine, particularly when coupled with public health initiatives enacted by the state, can create a contentious relationship with certain sectors of the public they attempt to govern. Communities that disavow mainstream medical dogma are often seen as unruly and deviant, and the backlash against them only further exacerbates the tension in this dynamic and alienates these groups. Examining the ways that these communities construct their images of "wellness" and "illness" can aid in a more thorough understanding of past failed attempts at top-down outreach and "education" in these communities. As David Hess explains in *Undone Science,* standard methods and ideologies of positivist-centric science see the public as "lay opinion," and "the solution from the elites' perspective was public education and the transmission of knowledge to the great unwashed under the assumption that greater knowledge would lead to greater public acceptance" (Hess 2016 pp. 6-7). This push towards "education" does not reach the target audience, and sometimes can further alienate them, or does not engage with its nuances in opinion and identity. Additionally, exploring how these subcultures come to conclusions that sway them away from allopathic medicine, conventional scientific evidence, and mainstream medical procedures can raise future questions concerning the heterogeneity of these groups. Though they are often lumped together and treated as a monolithic cluster, this research demonstrates that despite their unifying characteristics, they instead represent a variety of identities, and are motivated by a range of values, beliefs, norms, and ideologies.

Dissecting claims that do not fit in with the normative and conventional experience of the world (e.g. the earth is not flat, vaccines are effective and necessary, faith healing isn't a replacement for doctor visits, etc.) is inherently challenging. The notion that conventional "realities" are antithetical to the functional realities of medically "deviant" groups represents an

actualized form of postmodernism that confronts "science" itself as an institution. "Anti-science"

movements, a term used both within these groups and from outside them to describe those who

ideologically and behaviorally reject conventional science/medicine, are not exclusive to low

SES communities or rural communities—for instance, a large proportion of anti-vaccine activists

live in urban, wealthy parts of California and piggyback off new age "holistic health" ideals

(Yang et al. 2016). Additionally, though the bulk of these individuals have lower educational

attainment than their mainstream counterparts, those of lower SES who avoid vaccines tend to do

so because of lack of access to healthcare rather than steadfast belief (Berezin and Eads 2016).

This is, however, just one element in the diverse pool of anti-science communities—their

motivations vary depending on a multitude of culturally and socially situated factors. The

dominant narrative of the "anti-science persona" tends to be this image of an affluent anti-

vaxxer, and that eclipses this diversity, to the detriment of a potential better understanding of the

nuances of identity and belief within these movements.

The study of movements that reject mainstream science typically focuses on those who

have been historically disenfranchised or otherwise abused by the medical enterprise (whether

through forced experimentation, abuse in clinical trials, purposeful neglect, or outright racism).

This context makes for a convincing case against the medical industry from a group that has been

historically disenfranchised by that institution. The research presented here, however, focuses on

clusters of people who are typically not of a historically disenfranchised group. It has been

shown, for instance, that many anti-allopathic medicine holistic healers are conventionally

secular, urban city-dwellers (Oliver and Wood 2014). Meanwhile, many flat-earthers and faith

healers are religious Christians in rural areas. Though the sentiments in these waves of "anti-

science" groups should not be conflated with the fear of medicine in a historically discriminated-

against group, they are similarly motivated by a desire to combat this paternalistic place of science and medicine in American health policy and culture. This allows for the construction of anti-science sentiment as an exercise in power dynamics, positing science as an arm of the state, such that anti-science groups question this power and confront it.

In this way, examining the ways that these groups construct health, wellness, and illness requires an exploration of agnotology from several perspectives. Agnotology, described by Robert Proctor (2008) as the cultural production of ignorance, will be important in this examination, but arguably more important is the *perception* of agnotology from within and without these groups. While many outsiders view these individuals as problematic, or even a threat to public health, perhaps epitomizing agnotology, insiders in these groups see the conventional sense of knowledge—even science's most fundamental "rules" and practices, and its underlying ethos—as the grandest form of agnotology, and the normative individuals who buy into the mainstream ideology as perpetuating this ignorance for the masses.

That all being said, these anti-science groups are certainly not monolithic in their views or identities. The public narrative of anti-vax sentiment, as mentioned earlier, highlights the loudest voices and most-frequently-cited tropes. As Judy Segal (2008) saw in her examination of breast cancer narratives, there is a story arc to the common narratives that are adopted by these movements. They suggest behavioral patterns in the navigation of, say, anti-vaccine sentiment; they answer the question of "how" to perform this experience (Segal 2008, p. 16). In the case of anti-vaccine sentiment, the public stories follow the same generic arc: someone trusted the government, the medical industry, and vaccines, and then their child experienced vaccine injury, prompting them to reject vaccines and subsequently uncover a host of "truths" about the medical

industry, scientific community, and government, putting them in an elite group of those who "know."

There is a great deal of heterogeneity, though, in how these groups perceive both their inner circle's ideology and allopathic medicine. The groups are not uniform, and treating them as such erases the nuance in their beliefs. However, these groups' ethos is not fundamentally different from that of biomedicine. Both biomedicine and anti-science groups attempt to fight what they each see as agnotology. In the case of anti-science movements, this seems to be the active fight against ignorance—from their vantage, they fight the agnotology produced by the science-government conglomerate power structure for the masses. In addition, they are fighting the stigma of being active "biodefectors," or those who "reject biologically based citizenship" (Benjamin 2016, p. 968). This demonstrates a fight against "strategic ploy/active construct" agnotology by the state (Proctor and Schiebinger 2008 p. 3). Where many of us accept "passive construct" agnotology, at least implicitly (p. 6), the effort against "active construct agnotology" is an equally active one. Where this group sees the government and science as actively producing ignorance for the masses, their truths are the tactical battle against that agnotology, and by extension, against that dominant power structure.

This translates easily into the image of an active effort against what is seen as the oppressive state asserting medical dogma onto an actively fighting religious community. Given that most of the extreme anti-vaxxers, faith healers, and flat earthers I spoke to or encountered online for this research are very religious Christians, this appears as a power struggle against the paternalistic arms of the state.

The government's imposed vaccine laws, or encouragement to visit the doctor, or placement of the medical/scientific world as "unbiased"—these are all tangible fodder for the

ideological battle against the power structures that implicitly allow these dominant ideas to be accepted into conventional behavior and knowledge. Ruha Benjamin saw this in action in her examination of informed refusal and biodefectors when examining a family's refusal in a sickle cell clinic: "she doesn't believe they will ever find a cure, because scientists don't acknowledge the ultimate spiritual source of cures; by seeing themselves as the source of cures, researchers sabotage their own success" (Benjamin 2016 p. 973). She goes on to explain that many would see this as distrust of the medical world, but it instead could represent her trust in religious methods of healing and protection (p. 973). This is exactly what goes on with faith healers in particular: it is not mistrust alone that motivates them against conventional science, but rather *trust* in an alternative. It incorporates a whole world of extreme trust, rather, in one's own faith.

Again, these groups have a wide variety of viewpoints and feelings towards mainstream medicine and science, as well as trust and mistrust. Though many in the communities I examined founded their rhetoric around ideas of trust and mistrust, there was often an underlying (and perhaps implicit) notion of trust in religiosity. This in itself is formulated as an active move against state power, in that state power can strip religious communities of their right to informed refusal. These communities, then, can be seen as biodefectors much in the same way that Benjamin's are, despite the minutiae of these groups' identity differences. The medical community's wariness towards biodefectors provides for secondary, compounding ground on which these biodefectors feel obligated to embrace their alienation from the conventional medical world.

The objective of this project, then, can be achieved by taking these groups seriously through a look at the routes they take to arrive at their claims, and how they disseminate information about these claims. The aim is to formulate an understanding of the functional

schema these groups utilize to create subjective "truths" that reflect their collective identities. This entails investigating the communication patterns and rhetoric, underlying motivations and values, and aggregate construction of illness and wellness in these anti-science and anti-medicine communities.

In more detail, the aims are as follows: first, to investigate the core principles, values, and ideas that motivate individuals to follow unconventional approaches to health and healthcare. Demystifying these communities means recognizing that their members are similarly arguing against agnotology, and are motivated by the same core values and principles as their out-groups (fear, protective instinct, familial values, and the like).

Second, to investigate how and why anti-science/anti-allopathic medicine ideas spread in a postmodern context, where awareness of the "post-fact" paradigm is heightened, and both conventional and unconventional groups operate within new modalities to formulate what is "real" and what is "ignorance." The aim is not to investigate the dynamics of where web traffic occurs on these topics, but rather to explore the rhetoric and lexicon of these communities.

Lastly, to explore how these communities construct illness and wellness, and how these particular ideas become strong conviction/subjective "truth" within a community. The in-group dynamics of trust facilitate a greater sense of empathy and therefore "collective truth" within the community. Additionally, this requires an exploration of the perception of agnotology from within and from outside these groups. This sort of exchange and common ideology (not just in anti-science groups, but in other sectors of society at life) naturally begets the flow of ideas and strengthening of solidarity.

METHODS

Two major methods were employed for this research: ethnographic research consisting of semi-structured, in-depth interviews, and content analysis of posts, pages, and information on websites concerning anti-medicine and anti-science subject matter. Observational data, and interview-style conversations without any identifying information, were collected. This contemporary context necessitates this two-fold approach to investigation: because much of this information sharing occurs online, one part of this research by necessity was a content analysis of online sources. Second, preliminary searches yielded results pointing to a strong youth cohort, particularly in the areas of homeopathy and, surprisingly, faith healing. This suggested that ethnographic research in the form of participant observation and semi-structured informal interviews in youth-centric, faith-healing-oriented Christian congregations would be ideal.

Participant observation

IRB approval was obtained to conduct semi-structured interviews and collect online data. Churches were selected using three criteria: (1) access, i.e. availability to outsiders, (2) consistent expression of some degree of anti-science or anti-medicine sentiment, e.g. encouraging faith healing over doctor visits, and (3) activity online, given that many of these "real life" instances of communication transfer onto the online world as well, and are demonstrative of a consistent communicative philosophy. Congregations that committed strongly to this idea of spreading information about their core values were emphasized (e.g. post daily on social media, have over 25,000 followers, etc.). This research is primarily concerned with the limbo between what's seen as "fringe" and mainstream, because these can be very revealing of methods of communication that bring people into the community. These congregations are also more welcoming to outsiders. As this research is concerned with communication methods both on and offline, and

millennial-age congregants are more likely to engage with the church as "brand" online, these communities were also appropriate to that end.

Ultimately, two "house churches" and one larger congregation were identified. A "house church" in this context can be defined as a typically youth-centered congregation that is a piece of a larger Christian congregation. These house churches meet in relatively small spaces (sometimes homes, sometimes meeting spots, reserved locations, event spaces, and the like) and are grassroots, organic organizations. Each one was visited twice, and observational notes on the atmosphere, aesthetic, language, and experience were taken. All identifying information was redacted. After each visit, subjects were randomly stopped and interviewed according to the semi-structured guidelines below (Figure 1):

Figure 1.

Questionnaire for in-depth, semi-structured informal interviews

[PI will first verbally confirm that subject is a legal adult, and will explain that no audio or visual recordings will be made. All names, locations, and particular group names will be redacted in any notes. PI will confirm that everything will be kept anonymous.]

1. How did you find out about this group?

2. What is your primary mode of communication with other members of this group?

3. How would you define "illness" in your own words?

4. How would you define "wellness" in your own words?

5. What is your opinion on the practice of faith healing?

6. Do you feel that this community has helped you formulate these ideas?

7. How do you benefit from being a part of this group?

This allowed for five in-depth interviews with churchgoers. They revealed information concerning motivations for joining the church, their opinions on faith healing and conventional medicine, how they stay up to date and connected with the congregation, and fundamental philosophies underlying their continued drive to be part of this community.

Content Analysis

Using one initial primary source found on social media, other popular sources (e.g. websites, Facebook pages, Instagram profiles, reddit accounts, blogs, informational pages, organizations, religious groups' sites, etc.) were identified. Additionally, a web search was conducted to diversify the pool of data. Search terms included: anti-vaccine, truth, science truth, homeschool, homeopathy, holistic healing, wellness.

Because the unit of analysis is a particular post on a webpage, and the posts vary in nature depending on the site, I will refer to a statement on a website, a post on social media, a quote from a testimony, information on a blog, etc. as an "instance." A total of 728 instances were identified (all data was posted before February 16, 2018). A random sample of 200 of these instances was chosen for analysis by assigning each instance a number and pulling a random 200 of these numbers.

Three major anti-science/anti-medicine categories were created: (1) flat earth forums, anti-government science agency pages (these two often go hand in hand), (2) anti-vaccine forums, homeopathy/anti-allopathic medicine/holistic healing, (3) faith healing and anti-medicalization forums. Instances were coded with respect to the category they best fit (i.e. the primary purpose of the page/site/post), despite significant overlap. Though the categories naturally are intertwined, I did this so that I could attempt to have an even distribution of devoted primary topics in the original 728 (i.e. the "category" of anti-sciences) of these instances. Of the

200 instances that were randomly pulled from the 728, then, the distribution was as follows: 70 instances were pulled from category 1, 58 were pulled from category 2, and 72 were pulled from category 3.

Instances were coded for frequency of various themes, values, and contents with misinformation (Figure 2). To qualify as one "count" in the frequency count of instance contents, the instance had to specifically mention the theme or value in the category (for example, to count an instance in the "mistrust in government" category, the instance would have to specifically address their mistrust in government). Instances could count for as many categories were applicable, as this showed both the diversity and overlap in substance of these instances across the spectrum of topic within anti-science/anti-medicine.

RESULTS

Participant observation

Three prominent Christian congregations in Nashville were visited two times each (for a total of six visits) during worship context and after. Each one of the congregations is part of a youth-centric and tech-savvy movement, as mentioned earlier, that organizes around a very particular millennial Christian aesthetic. They have complex and smooth graphics on large screens during sermons, often are organized around music, and speak of lofty spiritualistic values and nebulous overarching ideas of "connection." They appear to—like their online counterparts in the holistic health movement—mobilize around "holistic community values," a term commonly used in various forms. Though they are commonly called "house churches" and this term is well known in the lexicon (and two in this sample met this criteria); some identify as "collectives."

The two house churches were remarkably similar: though one took place in someone's home and one took place in a rented meeting space, the environment was similarly warm, comfortable, and inviting. As a newcomer, I was introduced to hosts, organizational leaders, pastors, and other members of the churches. At the conclusion of the visits, pastors would do some sort of interactive event—either calling upon individuals in need of healing from sickness, or personally greeting newcomers in front of the congregation, or handing out Bibles. Much of the rhetoric focused on holistic healing: healing of body, they often explained, necessitated healing through spirit—quite literally, through the Holy Spirit, according to the majority of the subjects. Interviews and conversations were not recorded, but notes were taken during and after the visits.

In order to maintain the anonymity of the locations, I will not attribute specific experiences or quotes to any of the three locations in particular. The content observed and collected (via copious observational notes) at all three, however, was very similar. Some moments were brief glimpses into a romanticized version of modern Christianity. Jesus and God were generally not discussed in archaic, lofty terms; they were "buddies," "best friends," "homies." This was a benevolent character—"he's [Jesus] got our backs" was a common slogan. When one individual was asked how she came to believe in faith healings, to which she responded with an anecdote: "I had a God moment at church." According to her, a man with a severely broken leg asked for prayers, and the congregation leader asked the attendees to pray around this man. Once the pastor placed his hand on this man's head, he got up and walked away perfectly. She explained further:

As a pretty rational person, I cannot deny that God exists when I've seen miracles happen. When the guy in front of me in church completely healed of a busted knee from some—not even the whole church but just a couple—of us praying over him for a few minutes, I cannot deny that God is powerful and moving through the church.

Many of the subjects indicated a sort of ambivalent tone towards conventional medicine and vaccines, and utilized these begrudgingly. One man told me he didn't "believe" in shots. He didn't seem too strongly convinced, however: "I just don't think they work—I don't believe it. I honestly think prayer is just as good," he told me.

Many of them expressed a desire to adapt the Bible for the 21st century. They overwhelmingly supported common rallying points of the political left that don't tend to sit well with older Christians: gay marriage, immigration reform ("if we're pro-life, we need to be pro-life for everyone"), women's rights.

These predominantly young people occupy a peculiar duality in a contemporary context that does not necessarily see young people as religious. Many of them were college students, indicating trust and belief in the value of higher education, yet preferred faith healing to medicine. Additionally, many informants indicated hearing about these congregations from friends or relatives who were members, those original members having heard about it through social media. Strong personal experience was the most common precursor to conviction of the value of faith healing, as several informants indicated:

"I heard about [this congregation] from my daughter, who learned about it through a friend. They loved it so much. I was like, 'I have to check this place out because my kids just joined a cult, and I can't have that.' So I talked my husband into going."

This informant then described to me a trip she took that was only supposed to last several days, but left her temporarily stranded because she got very ill:

"I got sick. Which, I very seldom get sick. I went to the doctor, to urgent care, getting on IVs. I finally feel better and come home, then I relapse. I'm told I have a virus and also am full of infections. I have a 103 fever and a migraine. [The doctor] gives me all these shots and medicines and takes blood. This was a Saturday. I go home and he calls me and says my liver and kidney numbers are elevated and to go see my primary care doctor."

At this point, she expressed an intense exasperation and explained her desire to avoid the doctor,

but knew she would go anyway, despite her hesitance:

"I wake up Sunday and I said, you know what, I'm going to church. I do not care. I'm dragging myself to church. I feel horrible. My husband goes, 'you're not going to church.' So I watch [the live stream of the church service online] and it was amazing. Holy spirit all over my house."

She went on to describe a transcendent experience she had, feverish on her couch, while

watching this live stream, using the word "connection" quite frequently.

"Then [a prominent pastor in the congregation] walks onstage. And he says, 'I just feel like there is someone who needs healing. They have…a migraine. They have…' and then he starts listing exactly [all my symptoms]. I'm rolling on the floor crying and I manage to whisper, 'Jesus I accept my healing. I'm receiving my healing right now. Because you know what he said was for me.' Then I wake up Monday and I feel…I feel different. I feel like I've turned a corner. I'm healed. I go to the doctor later that week and they want to do blood work. They call me the next day and say everything is perfectly normal. And I said 'I know, I was healed.'"

She concludes that this is what led her to her belief in faith healing, and her resultant hesitance to

go to the doctor—that being said, she said she still believes in medicine as an idea and will go to

the doctor if necessary. She places ultimate faith, however, in the power of God and God's will;

when it comes to illness, she explained, the outcome is up to the will of God.

I interviewed one of many pastors who preaches at one of the congregations frequently.

Within the context of the interview, she paraphrased a strong belief about "pain, illness, and

suffering" that she says guides her sermons:

"We don't like feeling pain…our generation doesn't like to push through anxious thoughts. We medicate ourselves, we numb ourselves…we are the most medicated, most stressed out, most run down society that has ever walked the earth. Pain must serve a purpose, pain must take its course. When we 'painkill,' we're just delaying the inevitable….God said pain will come. And consider it pure joy when they do. So, when we suffer, we're not meant to say 'God where are you,' we're meant to say God, what is the purpose of my pain.'"

She explained that she sees pain and sickness as having a distinct utility, and that it is up to us to

determine what that utility is more so than it is our burden to heal it. She also expressed

grievances about the hypersensitivity of "our generation" quite frequently. She went on to

paraphrase, in her words, some of these principles that guide her.

"I'm not talking about self-inflicted pain. The way I see it, that's just consequence for sin. I'm talking about random pain that comes out of nowhere. Like, sickness that just falls on your body. That sickness is not from God. I believe it's from Satan. But god will use it to teach you. Sickness and pain increase your capacity and bring you into maturity."

She went on to allude heavily to Joseph in the Bible, enduring pain in the name of salvation. She

used rhetoric frequently of "humbleness," indicating that pain and illness keep one "humble,"

and prevent us from becoming "arrogant" or "conceited." Two other informants echoed that

sentiment. She took a literalist interpretation of "God's voice," and this seemingly informed her

construction of illness as a utility in the theological sense:

"Have you ever met those people who are prophetic or hear from god? Some of them are kind of arrogant sometimes because they're like, 'I hear god better than anyone else'…that is what I want to avoid by seeing illness as God's way of using Satan's work for us."

She informed me that she prayed for pain, in fact, to keep her humble. This all heavily relied on

the narrative of utility for sickness and illness. The way to combat it and present a sense of

"wholeness" is to "do the opposite," she said:

"We need to do the opposite of everything the world wants you to do. When a sexual abuse victim is able to forgive their abuser, glory is revealed. That's something I like to mention when I preach. When you've been robbed or struck down but you forgive and bless, glory is revealed. We need to be grateful for sickness, even if it's difficult."

Additionally, informants described that they relied heavily on social media, and then secondarily

on word of mouth within the Christian community, to spread the word about their congregations

and groups. Some of these statements had moral undertones or overtones:

"It would be wrong of you to not spread Jesus to your friends if you know someone who doesn't know Jesus… if I knew the cure for cancer I wouldn't keep it in my household alone. I would give it to every single person, even if I didn't know them. I'd be shouting it from the mountaintops."

This was a particularly direct comparison to the medical world. Even if not intentionally, statements like this create the implication that a life without belief is akin to "cancer," in a sense. Much of medical rhetoric was placed secondarily to faith healing, or in the context of specific scripture. Scripture, it appeared, justified the circumvention of Jesus' will alone to heal the sick, and conditionally allowed for reliance on doctors and medicine. Another woman who felt particularly close to her commitment to the power of faith healing described her experience as follows:

"I was in my car on the way home. I went to [the church's website] to look for a sermon. I'd been searching for healing from trigeminal neuralgia for several years. It's a facial nerve disorder that's often called the 'suicide disease' because of the intense pain it causes. I've been through surgery for this, but that's only temporary. I went on strong medication that masks the pain. But the side effects of those pills have been as debilitating as the pain…I felt such a shift in my spirit listening to the sermon. The power of it was so strong that I pulled my car over and pressed my face to the ground and cried out for healing, for real. I wept a ton."

She explained this was a transformative point for her and, like other interviewees, pointed to forgiveness as a saving grace, explaining that she abandoned frustration and fear in favor of forgiveness. She continued:

"I came home and decided that day to reduce my medication, because I realized that my dependence on that pill was greater than my dependence on God. The fear of pain not taking my medication was greater than my hope of healing. Normally, if I reduced meds for 2 days I'd be writhing on the floor in pain. But instead…a month went by, no pain….I learned being physically healed is only half the process. Healing can't happen without a realignment of the heart. The dependence I had on my medication is being replaced with a dependence on God."

Social Networks

The structure of these churches is incredibly intimate despite the relatively large size of the congregations (each house church controls their capacity, but they are all members of a larger organization that may very well be considered a "megachurch"). They rely on word of mouth, friends telling friends, and very active social media presences. They also put on appealing events that resemble things like music festivals; sometimes they'll host parties and camping trips. One

congregation, for instance, hosts a yearly music festival that can cost hundreds of dollars to attend.

Surprisingly, then, a lot of the information exchange happens in these informal settings. They go out to dinner; they hang out outside of church. As one individual interviewee explained: they organize online, yes—but the casual inclusivity and yet specialness of these communities is conducive to a "safe space" for an idiosyncratic blend of religiosity and urban youth. This blend included a kind of nebulous spiritualism in addition to traditional Christianity, the former which informed their approach to "wellness" as being at peace with body and spirit and the latter as being at peace with "the Holy Spirit" in particular.

Online data instances and content analysis

Interestingly, there was significant overlap in subject matter and concerns discussed in the interviews and in the online data. However, the hostility and intensity with which individuals held these convictions was much greater online. This is not surprising. The mask of anonymity online—despite the reassurance in person that names would be redacted—facilitates a kind of openness and vulnerability that is difficult to engender face to face with a stranger.

Figure 2 shows the results of the coding schema as described in the Methods section (on following page):

Figure 2.

SOURCE OF INSTANCE (*n* = 200)	Number of instances, *n*	Percent of instances
Facebook (of any anti-science/anti-medicine category)	133	66.50%
Instagram (of any anti-science/anti-medicine category)	25	12.50%
reddit (of any anti-science/anti-medicine category)	8	4%
religious organization website/social media	17	8.50%
informational website/blog	15	7.50%
other organization website (e.g. newsletter)	2	1%
THEMES (not mutually exclusive; an instance could fit multiple categories) *(continued on following page)*		
CONCERNS ABOUT…		
government or government agencies (e.g. NASA, CDC)	106	53%
conventional health as an idea or institution	113	56.50%
doctors or scientists (often lumped together)	149	74.50%
schools, school as a concept, universities/colleges	47	23.50%
research, science, "evidence-based medicine"	164	82%
specific medications/treatments/procedures	14	7%
groups of people (e.g. ethnic/religious)	12	6%
(cont. on following page)		
CONTENT		
messages about chemtrails	22	11%
concerns about conspiracies to keep populace mind-controlled	23	11.50%
general surveillance concerns	26	13%
general doomsday predictions	2	1%
VALUES		
individual liberty	111	55.50%
bodily autonomy	73	36.50%
balance (between self & society, religion & science, etc.)	45	22.5%
protection of children/familial integrity	124	62%
religious or spiritual values	92	46%
MISC. INFORMATION, with links to unverified sources		
vaccines contain aborted fetuses	28	14%
vaccines cause autism	132	66%
"medicine is what makes you sick"	59	29.50%
alternative medicine and holistic health guidelines/ideas	42	21%
faith healing as exclusive means of wellness	31	15.50%
exaggerations/sensationalism (e.g. "this will change everything; everyone is in danger")	3	1.50%

Coding the data this way—as opposed to grouping them by category of anti-science movement and analyzing them within the context of their groups—allows for a larger look at how this rhetoric transcends specific "goals" within the anti-science world, and is rather present despite varying degrees of commitment to these goals. For example, flat earthers, non-religious holistic healers, and faith healers all used rhetoric of autonomy and individualism, frequently citing the significance of the "principle" of being able to make ones own decisions about what goes in the body.

Roughly half of the instances had rhetoric espousing mistrust (and sometimes even hatred) for government agencies. Many of these overlapped with mistrust of health as an institution (56.5% of instances) or conventional science (82%). Some examples of things that contained this rhetoric are below:

"NASA admitted that they used photo shop on there [sic] *images. An* [sic] *there are only 3 full images of the planet. They are not a real agency. That is literal fact!!!"*

"I feel blessed that nothing bad happened to my son almost 45 years ago when we trusted the doctors AND the government."

"Getting into the technicalities as far as physics and whatnot in order to debate the topic of globe earth vs flat earth is redundant, at least to start off with. Start with the foundation of things. The foundation and origins of heliocentricism have already been exposed as well, and unless you're a pagan, polytheist or sun worshipper, I don't see how you could follow that sad excuse of a scientific theory. If you support the globe revolving around the sun theory, I highly advise you understand the origins of Heliocentricism and of course our dear friends, NASA."

Many professed a distaste for the "indoctrination" in public schooling, but still wanted their children to understand what conventional science is. Again, they stressed this balance:

"I'm not homeschooling yet but probably will. My kids are still 2&4 but we've stopped vaccinating so I'm pretty sure we won't have a choice but to homeschool. And if that's the case, yes I'm going to teach them the biblical flat earth cosmology as well as young earth creation. I'll teach them the world view as well so they know and understand the deception. I think they'll need to know both views."

"I'm not on [sic] *a position to home school, but they are in Christian private school. Even with that, I spend a decent amount of time correcting theology and teaching the other side/rest of science."*

"My daughter goes to public school because home school isn't a option at this time. She goes to school with 12 other children (All within 2 grades of eachother) [sic] *who are taught Flat Earth at home. Thankfully we have found a group of people (who work together and send kids to the same school) who believe in Flat Earth. We allow them to know the earth science taught in school so they can better understand our biblical Flat Earth. It's amazing to hear them dispute it. My daughter says they are special because they know both sides of the story."*

Some had a very literalist interpretation of healing, and saw a holistic healing practice as achieving "wellness" through "balance." One religious Christian blogger explained her relationship to speaking in tongues:

"I took [a class about the Holy Spirit] and prayed to God that I was ready to receive my prayer language even though I didn't know what it would look like. And he sent me three little words. And I was so happy, I prayed over them over and over. And then a few months later, I was at my best friend's house and I spent the night, and another friend had a night terror. And so we all prayed for her, and then at the end of that, God told me He wanted to give me my full prayer language. I told my best friend and she prayed, and then it all came out of me as a torrent. This helped me through my nightmares and sleepwalking habits. I was able to sleep at peace."

There is a huge overlap between those who reject conventional scientific evidence/medical dogma and anti-vaxxers. These users indicate some of their ideas surrounding that, as well as some ideas about how wellness is defined and illness is avoided. Many of these also include instances within the category of "misinformation." For instance, many flat earthers also deny the existence of gravity itself, and believe it is all a hoax. Additionally, they are very wary of doctors:

"I've long said that the best strategy for achieving health is avoiding a visit to your doctor in the first place. Why? Because in many cases you will simply leave the office with a prescription or two, which will rarely solve your health problem. Most doctor visits result in 'solutions' that only suppress your symptoms, often causing other side effects and problems. Rather than advise patients about the true underlying conditions and real solutions that lead to health, they are left putting toxic Band-Aids on gaping wounds…there are actually many reasons why avoiding your doctor may be in the best interest of your health."

Note: this was posted by a prominent figure in the flat earth community, whose website also features a detailed section concerned with denying the Holocaust. There is demonstrative overlap between these populations and racist and/or anti-Semitic groups.

"As for gravity, it does not exist. If you fill a balloon with helium, a substance lighter than the nitrogen, oxygen and other elements which compose the air around it, the balloon will immediately fly upwards. If you fill a balloon with hydrogen, a substance even lighter than helium, the balloon will fly upwards even faster...Now, this has absolutely nothing to do with "gravity." The fact that light things rise up and heavy things fall down is simply a natural property of weight. That is very different from "gravity." Gravity is a hypothetical magnetic-like force possessed by large masses which Isaac Newton needed to help explain the heliocentric theory of the universe. The theory of gravity was debunked by General Relativity. The theory of general relativity was debunked by Flat Earth."

Many expressed abhorrence for vaccines at all, both for what they are ("autism-causers," for

example) and what they represent (an apparent threat to autonomy). They also expressed the

false idea that vaccines contain aborted fetuses:

"It's hard to believe in Jesus and the Bible, and also justify injecting your children with DNA from aborted babies."

"It's sad many Christians aren't aware that there's aborted fetal cells in vaccines or they don't believe it because the government 'wouldn't do that' and 'cares about them'"

"I don't see how anyone can think [vaccines] are good! 20 years ago when my son was born, I didn't want them to stick him! It felt wrong in every way! God made us perfectly in His image! I'm sure He despises vaccines!"

"God is definitely against abortion, which is required to create vaccines"

"So many believers think God gave us vaccines when in reality God made us with perfectly capable immune systems that don't need the interruption of toxic vaccines to 'help' keep us from getting diseases."

"All FE [flat earthers] are anti-vax. The only non-woke thing I've seen FEs do is support Trump."

This is a potentially unexpected example of anti-science movements' disdain for all government,

including Donald Trump. However, many expressed that Trump is not religious enough, and that

is the cause for their disdain for him.

"I believe vaccines neurotoxins are the ones keeping us dumb and unable to do critical thinking and be forever sheeple, its [sic] *just by God's grace He gave us wisdom and strength to stand for the truth."*

"The vaccinated get these diseases far more than the unvaccinated. getting an illness isn't child abuse, but injecting them with poison is. I have one vaccine-injured child."

Many of the websites concerning the most intense anti-science thought also had deeply anti-Semitic undertones, wrought with ancient stereotypes and repeated statements about the "power of the Rothschilds" that "we must beware." 12 (6%) of the collected instances professed mistrust in "groups of people." In all except one, that "group of people" was "the Jews," described as an "elite ruling class" that "controls all media and government."

There is a definite pattern in "rabbit hole" thinking, that being, one anti-science or anti-medicine movement begets the "waking up" to the next—a type of learned communication once a member of the in-group:

"Vaccines were what lead me down the rabbit hole, which eventually lead me to FE"

"Vaccine research was a gateway drug into the rabbit hole!"

"The snowball effect is why they don't want us awake to ANY of their deceptions. Once you tear the veil, we can see that they've lied about many other things too."

DISCUSSION

Medicine and science are non-teleological methods to create, in some sector of society, social order: population health as a conceptual goal is in the best interest of both individuals and the state, but the practical means to that end are seemingly messy. Its esoteric and jargon-laden minutiae are, reasonably to any outsider, shaky ground on which to place essentially blind trust. As these results demonstrate, there is an increasingly visible culture that asks: why trust this institution—perhaps seen as a direct arm of a "ruling class" type of group—over one's own inner circle?

Evidence: creating "truth"

Naturally, there are some glaring answers to this question: if you don't trust *them*, trust *evidence.* This, however, exists in a world where the operational definition of "evidence" aligns with that of the conventional scientific enterprise. The misalignment in ideology is *not* in that these groups refuse "evidence" conceptually, but rather that they question the notion that those who have the authority to create and confirm "evidence" should necessarily have that power.

Though they have different motivations than academic post-positivist movements today, they rely on similar ideas surrounding the historical and political context of the evidence that is revered in the scientific world. As Sandra Harding simply states in *Objectivity and Diversity,* "sciences and their philosophies have never been value-free" (Harding 2015 p. 2). Arguing that recent political and social uprisings should be included in the contextualization of philosophies of science, she explains, "[these movements] want a say in transforming the conventional philosophy of science and its blind allegiance to elite social projects into philosophies that actually serve their interests" (p. 4). Though movements I examine here are quite different from political uprisings arguing for more social justice and progress, they have similar motivations. Simultaneously, science as an institution is unlikely to immediately abandon its positivist principles. Perhaps what these movements implicitly ask instead, then, is for an uncoupling of science/medicine from its historically-rooted political paternalism—or, for it to be less opaque and more accessible to the diverse masses.

Steven Epstein explores the actors who get to make credibility claims—and the problem of citing "evidence"—through the lens of HIV/AIDS in *Impure Science*: "The extent to which closure is achieved," he explains, through citing "evidence" of an epidemiological study to dispel worries about drug efficacy, "depends crucially on the capacity of actors to present themselves as

credible representatives or interpreters of scientific experiments—to ensure that others trust their evaluations and will fall in line behind them" (Epstein 1996 p. 334). Additionally, the media plays a major role not in reflecting credibility hierarchies, but also creating them. "Media designations of who counts as a spokesperson do not simply *mirror* the internal stratification of a social movement or a scientific community, but can even *construct* such hierarchies" (p. 335). The interpolation of media attention, political pressure on media, and political control of science and public health creates actors entirely alienated from the communities they govern. While it is easy for "experts" to place blame on anti-science communities for alienating themselves, it is just as evident that the alienation cuts both ways.

In his book *Cigarette Century* (2007), Allan Brandt describes the ways that the tobacco industry lobbied so aggressively as to prevent any real legislation against it until the 1960s. Using well-known lawyers and "expert witnesses," the interpolation of state power with the perceived expertise of these witnesses with vested interested delayed tobacco legislation to the detriment of public health. In the midst of the "largest civil litigation in the history of American law" (p. 496), he read expert witness statements from distinguished medical historians: "I was, quite simply, astounded by their 'expert statements.'…Neither had ever published anything about cigarette smoking…I was appalled by what they had written. I found their statements to be poorly researched, inaccurate in their historical assessments, and highly selective" (p. 497). This is an example of one of the largest American industries using the power given to "experts" to lobby in their own favor. Egregious examples of misuse of expert witnesses exemplifies Proctor's idea of passive construct agnotology (Proctor 2008), showing who holds what information given these power structures, and then active construct agnotology, in how they exercise that power and purposefully withhold information. Consequently, examples like this one

allow for groups to make this point: that the health-state interpolation has given ample examples of treating the general public as non-experts, and using these artificially-inflated "expert" categories to exert control on the public. These anti-science groups implicitly define these structural forces that only give some the power to be experts as ground on which to break down claims and push back against these forces: "evidence," then, is really an exercise in power dynamics.

These groups, in their own way, then, do use evidence, even if their evidence at first appears antithetical to "conventional" scientific standards. They simultaneously want to appeal to conventional science and dissent from it, employing its lexicon without stepping into its world in order to make an argument (Holton 1993 pp. 153-155). In this way, these communities use their sources of evidence based on the entities they trust (God, religion, their own community leaders, etc.) in the same way scientific communities do. When conventional science appears as antithetical to their values, or seems to attempt to thwart their ways of life, they use "alternative" sources to combat these paternalistic power structures.

Autonomy & Defining Wellness/Illness

The more esoteric science becomes, the further alienated the general populace will potentially feel from it (Merton 1938 p. 333). When an entity from which a group of people feels alienated attempts to lay claim to their territory—whether that be religious, bodily, familial, ideological, physiological—it becomes paternalistic in the eyes of the group. This ethnographic data demonstrates that phenomenon in action: 55.5% of the sample of instances expressed "individual liberty" as an important value to them. Additionally, 74.5% of the sample indicated concerns about "doctors/scientists," often alluding to the hegemony inherent in medical hierarchy and the valued position given to doctors in society.

Aggressive individualism is a distinctly American value. This is a widely discussed phenomenon with complex historical roots, and has been chronicled through its potentially damaging effects (Spence et al. 1985). Individualism is, in a sense, a means to actionable autonomy: creating a niche space for oneself medically allows one to act freely within that space. Becoming part of a niche subgroup that champions faith healing over doctor visits allows for the social approval of eschewing allopathic medicine within that space.

Wellness, to many of these groups, is implicitly defined as the exercise of personal autonomy, a balance of self and spirit, a feeling of "ease" or "peace." Spiritual health seems as important as physical health to many of these individuals; in fact, many expressed that the latter cannot exist without the former. Illness is, in some ways, constructed as a lack of acceptance. Yes, physical sickness is illness, but this acceptance of it and trust in the constructed truths of a member's in-group guide the way to "wellness" (or at least coping through illness).

A great deal of the motivation behind these behavior patterns and worldviews can be found in this emphasis on autonomy. In Robert Merton's words, "science must not suffer itself to become the handmaiden of theology or economy or state. The function of this sentiment is likewise to preserve the autonomy of science" (Merton 1938 p. 328). This highlights an important implication that remains quite true today: that science, by definition, requires a degree of autonomy as an institution, or even a field of study. It does not set out to threaten the autonomy of individuals, but when is has actionable consequences (e.g. state-imposed vaccine laws, social pressure to go to the doctor, government-issued health guidelines), the autonomy of science seemingly threatens the autonomy of the individual.

Furthermore, when science-through-the-state goes wrong, and then covers up its wrongdoings, it does not assuage these groups' concerns about a paternalistic power structure

potentially damaging them. For instance, as Bookchin and Schumacker explore in *The Virus and the Vaccine* (2005), a huge group of polio vaccines were contaminated with a "carcinogenic monkey virus" that the government then denied was harmful. These kinds of events place the ventures of public health in the complex position of simultaneously trying to improve population health and being prepared to face the consequences of its lapses. This also allows for the medical world to further be perceived as a form of active construct agnotology (Proctor 2008). And when the "lay people" at large don't respond positively to the "education" efforts of these power structures, the scientific community sees anti-science movements as engaging in their own form of agnotology as well.

Again, this research demonstrates the diversity in expression, identity, and ideology among those in anti-science movements, something that the autonomy value highlights. Subscribing to movements that reject mainstream medical dogma is a way to confront active construct agnotology, and simultaneously an exercise in asserting the right to individualism and personal freedom—whether that be freedom of religion, of bodily autonomy, or perhaps even the freedom to become ill. Members of these groups justify claims using rhetoric that champions the power of autonomy: "mothers are the experts on their children's health, *not* the state"; "I have a right to say what goes or does not go in my body"; "us versus them" statements (which occur on both sides of the token). In religious communities, God and God only has this power of autonomy. Compulsory vaccination—or any top-down recommended medical care, for that matter—faces resistance because it appears inherently paternalistic, especially in the United States. Individualism as an American value can perhaps be considered a cause of both suspicion of government-articulated medical guidelines and consequent resistance to them. Regardless, a threat to this sense of power over oneself is a major motivating factor. Autonomy of science-in-

action and autonomy of self as citizen cannot seemingly exist in the same space, particularly while each group defines the other as an example of active construct agnotology.

CONCLUSION

My aim in identifying the values of autonomy and individuality in these groups is not only to explore their communication methods and how they define illness and wellness, but also to exemplify the ways that these groups are fundamentally heterogeneous in character, ideology, and identity. Previous studies (Kata 2011; Moran 2016; Oliver and Wood 2014; Poltorak 2005, to name a few) have looked at these groups. However, they predominantly treat these groups as monolithic, championing a common cause and representing similar identities. It is difficult not to, when the loudest and most visible voices are the going to appear representative. This research is, of course, valuable in that it takes those claims seriously and analyzes them. However, it does not allow for the representation of a wide range of identities and the diverse viewpoints, levels of "dissent" from mainstream medical ideology, or even just intersections with other views of theirs.

A great deal of the variation in these groups is in their relationship to doctors. It appeared that many had nuanced opinions towards doctors, each colored by personal stories and experiences in the medical world that either turned them towards or away that world. For instance, many faith healers were less wary of doctors, and focused far more on trust in a higher power than mistrust in anything else. Others, meanwhile, expressed a distaste for the idea behind doctors, implicitly questioning their right to making credibility claims in a hegemonic power structure that elevates their opinions. Some skipped over doctors entirely, seeing them simply as just one part of a machine that purposefully alienates them.

Structural conditions, then, inhibit certain voices as well, and allow outsiders to further see these individuals as a homogenous group. Religious groups have historically resisted state power, and the secularity of the state appears as another way to impose a different form of belief onto these groups. This sentiment allows for a degree of self-alienation, particularly for the religious Christians living in rural areas. Many of the rural Christians in this data collection expressed not only a lack of health insurance, but a feeling that they did not want to buy into a system that was trying to exclude them anyway. Allowing oneself to fit into the power dynamics inherent in the insurance-defined diagnostic schema, into medical treatments, etc. is akin to relinquishing a sense of self-determination. And that, according to one sector of these anti-science and anti-medicine communities, is akin to "illness" itself. However, this is a clear difference from the passivity and even indifference with which many *urban* faith healers regard insurance—even if they didn't have it. It is essential to recognize the diversity of opinions and ideologies even *within* religious groups that argue against conventional medicine. Erasing these differences and painting them as homogenous has not aided in "education" outreach efforts, and does not accurately portray the substance of their sentiments.

This raises a wide variety of questions for future research. How is the portrayal of these groups as homogenized not only to conventional science's detriment, but also steeped in the very paternalistic nature of state-sanctioned science that these groups confront? Where can public health campaigns improve in their treatment of these groups? How does this diversity manifest in medical behaviors? And, ultimately, when we define anti-science sentiment as resistance to power structures, it sets the stage for an exploration of how will future political, social, and ideological changes will shape that resistance—and how the state's idea of "health," and its actors, will respond to it.

REFERENCES

Bedford, D. (2010). Agnotology as a teaching tool: Learning climate science by studying misinformation. *Journal of Geography*, *109*(4), 159-165.

Benjamin, Ruha (2016). "Informed Refusal Toward a Justice-Based Bioethics." *Science, Technology & Human Values.*

Berezin, Mabel, and Alicia Eads (2016). "Risk is for the rich? Childhood vaccination resistance and a culture of health." *Social Science and Medicine* 165: 233-245.

Brandt, A. M. (2007). *The cigarette century: the rise, fall, and deadly persistence of the product that defined America*. Basic Books (AZ).

Epstein, S. (1996). *Impure science: AIDS, activism, and the politics of knowledge* (Vol. 7). Univ of California Press.

Harding, S. (2015). *Objectivity and diversity: Another logic of scientific research*. University of Chicago Press.

Hess, David. (2016). *Undone Science*: *Social Movements, Mobilized Publics, and Industrial Transitions*. MIT Press.

Holton, Gerald James (1993). *Science and anti-science*. Harvard University Press.

Kata, Anna (2011). "Anti-vaccine activists, Web 2.0, and the postmodern paradigm–An overview of tactics and tropes used online by the anti-vaccination movement." *Vaccine* 30.25: 3778-3789.

Merton, Robert K. (1938). "Science and the Social Order." *Philosophy of Science* 5.3: 321-337.

Moran, M. B., Lucas, M., Everhart, K., Morgan, A., & Prickett, E. (2016). What makes anti-vaccine websites persuasive? A content analysis of techniques used by anti-vaccine websites to engender anti-vaccine sentiment. *Journal of Communication in Healthcare*, *9*(3), 151-163.

Oliver, J. Eric, and Thomas Wood (2014). "Medical conspiracy theories and health behaviors in the United States." *JAMA internal medicine* 174.5: 817-818.

Poltorak, Mike, et al. (2005). "'MMR talk' and vaccination choices: An ethnographic study in Brighton." *Social science and medicine* 61.3: 709-719.

Proctor, R., & Schiebinger, L. L. (2008). Agnotology: The making and unmaking of ignorance.

Segal, Judy Z. (2008). "Breast Cancer Narratives as Public Rhetoric: Genre Itself and the Maintenance of Ignorance." *Linguistics and the Human Sciences* 3, no. 1: 3–23

Schumacher, Jim & Bookchin, Debbie (2004). *The Virus and the Vaccine: The True Story of a Cancer-Causing Monkey Virus, Contaminated Polio Vaccine, and the Millions of Americans Exposed*. Macmillan Publishers.

Spence, J. T. (1985). Achievement American style: The rewards and costs of individualism. *American Psychologist*,*40*(12), 1285.

Sismondo, S. (2017). Post-truth? (Editorial.) *Social Studies of Science,* 47(1), 3-6.

Yang, Y. Tony, et al. (2016). "Sociodemographic predictors of vaccination exemptions on the basis of personal belief in California." *American journal of public health* 106.1: 172-177.