

The Publics of Pharmaceutical Activism

A Research Paper submitted to the Department of Engineering and Society

Presented to the Faculty of the School of Engineering and Applied Science

University of Virginia • Charlottesville, Virginia

In Partial Fulfillment of the Requirements for the Degree

Bachelor of Science, School of Engineering

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Spring 2022

On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

Americans don't trust the pharmaceutical industry. It is the most negatively viewed industry within America, being ranked behind even the federal government with an overall negative view of 58% (McCarthy, 2021). This distrust of pharmaceuticals has been widely ingrained in American society since its introduction in the 19th century with the patent medicine industry. From this distrust a network of grassroots activism arose that still stands as the basis for pharmaceutical activism today (Batt et al., 2020). Pharmaceutical activism strives to alter the pharmaceutical industry by recruiting members of the public to campaign government and corporations to regulate and improve select areas of public health interest, primarily consumer health and financial issues.

The recent increase in distrust of the pharmaceutical industry, has led to an array of grassroots organizations that play vital roles in shaping policy within the U.S. The key governmental organization within the U.S. for the regulation of pharmaceuticals was founded as a consequence of pharmaceutical activism (Goodwin, 2006). This grassroots activism continued throughout the 20th century, although saw a decline due to increased trust in the pharmaceutical industry due to the implementation of high impact drugs like penicillin and vaccines (Akhtar, 2021). Arguably one of the key movements of the 20th century can be seen with the HIV-AIDS movement, which fought for public recognition and scientific advancements for the betterment of populations suffering from the HIV-AIDS epidemic (Sismondo, 2010). However, with the recent erosion of public trust in the pharmaceutical industry in the 21st century, many new pharmaceutical activism movements have arisen. Two key movements can be characterized by a very traditional drug pricing movement (Bartz & Stempel, 2020), and rather unconventional

movements such as the alternative medicine and vaccine skeptic movements, the latter of which will be the key movement analyzed and compared to historical movements within this paper.

To accomplish this goal a variety of grassroots pharmaceutical activism movements were analyzed under the lens of a Public and Participation framework, as well as, the lens of an women's centric embodied health movement. Public and Participation is characterized primarily by an analysis of the "process by which different aspects of participation are defined or constructed" (Hess & Sovacool, 2020, p. 10). It is heavily influenced by the analysis of shortcomings of public understanding of science and the interplay of the lay person and the expert. Further it is useful for defining characteristics that allowed publics to participate within social movements and how this participation ended up affecting wider civil perception and support of various movements, and the eventual acceptance or rejection by experts within systems (Hess & Sovacool, 2020). Embodied health movements are a form of health social movements which seek to address health issues by challenging science, and are usually comprised of three characteristics: the introduction of the body to social movements, challenges to existing scientific establishment, and activists collaborating with scientists and health professionals (Brown et al., 2004). Combining both of these lenses will allow for the establishment of the motivation for mobilization and the identification of the individual.

Overall, the goal of this paper is to compare a successful historical movement to the surprisingly successful alternative medicine and vaccine skeptic movements by comparing and contrasting key characteristics of the publics that participated in their movements. Utilizing this information conclusions will be drawn on how scientists can tailor their messages to prevent harmful activism, and how publics can be utilized to improve policy implementation of technologies and beneficial regulations.

Women Activists in the Gilded Age

Pharmaceutical activism within the U.S. widely began with the push by women's groups to form the Food and Drug Administration (FDA), since then multiple movements have sprung up lobbying for change within the industry. This initial movement is the quintessential example of pharmaceutical activism within the history of the U.S. and arguably most successful.

During the gilded age no effective government agency existed to regulate the patent medicine industry which, similar to other industrial staples, was rife with unadulterated abuse of consumers. To draw a comparison, Upton Sinclair (1906) famously highlighted the complete lack of sanitary controls within the meat packing industry, which similarly had no effective regulation. Americans were incapable of determining which consumer medicines were truly beneficial and which ones were harmful to the user. Simultaneously, the system was rampant with anti-consumer practices; astroturfing was commonly used in advertising, as highlighted by "They see my advertising. They read the testimonials. They are convinced. They have faith in Peruna. It gives them a gentle stimulant and so they get well." (Adams, 1905, p. 4). Compounding all of this was the rampant political corruption during the gilded age; before the rise of public participation in an activism process any accusations levied against industrialists would be disregarded by politicians (Batt et al., 2020).

In order to fight against this decreasing level of control among the populace of what was being consumed, 'the movement out of the house and into the factory', the first wide spread grassroots pharmaceutical activists were born. The 'Pure Food and Drug Crusaders' were characteristically women who, dissatisfied with the drug status quo, took up activism against patent medicine companies. The historian Lorine Goodwin (2006) identifies three main parts of

their activism: an initial formation of activism; the extent to which women cooperated across lines of affluence, religion, occupation, ethnic origin, and region; and finally, how these women overcame industrial and political opposition they encountered. Initially these women were driven by a key dilemma, how pure should the food, drink, and drugs that Americans consume be? At the time contaminated consumer goods led to spreading disease and child death, and patent medicine that was considerably dangerous was marketed as safe and effective. Relative documentation is scarce however one physician, David Paulson (1903) reported that half of delivered infants died due to preventable causes by age five, and that those who survived ended up being invalids.

While one of the large causes of this was adulteration within the food and drink industry, adulterated medications presented a greater and more immediate threat. Tonics, sarsaparillas, syrups and preparations made up an industry worth \$100 million dollars, or \$1.25 per person each year (U.S. Bureau of the Census, 1913). There was no scientific or medicinal background to many of the successful firms, they falsified curative powers, and specifically designed their products to be addictive, not unlike the recent opioid scandal that plagued U.S. pharmaceutical companies (U.S. Department of Health and Human Services, 2022). Recent studies indicated that clinical addiction occurred at a rate of 4.5 patients in one thousand, and that they were predominantly female and overwhelmingly white, 65% and 95% respectively (Courtwright, 2001). One key note is that consumers were driven to these proprietary medicinal because of a lack of trust in physicians who were seen as opportunists who would sell more expensive concoctions that were equally dangerous (Goodwin, 2006).

From a traditional sense of responsibility, women were in a unique position to fight for the implementation of consumer goods regulations. No one questioned the feminine role to

nurture well-being, and to some extent women had historically acted as a familial doctor, being responsible for care within the home. Further through this duty of care, women had already constructed networks of female kin, a consulting support service where if she could not handle the illness herself, she could seek those who had more understanding and ability. These networks were coopted for grassroots activism, with treatment moving from the home to the factory women utilized this preexisting knowledge to communicate which treatments were beneficial or dangerous (Goodwin, 2006).

With initial networks formed, a base strategy was disseminated throughout with a pattern of investigation, planning organization, agitation, perseverance, legislation, enforcement, and augmentation. The base unit of intelligent reform was seen as study, ‘guesses at science’ were seen as detrimental to the cause, as such each member should participate in a form of citizen science. In order to do this, these women’s networks setup their own decentralized departments heading programs of research. These departments were headed by medical doctors, and other scientists who were educated and prepared to study the chemical components of popular drugs, such as the discovery that a common cod oil medicinal in fact contained no cod oil but rather opium. These groups and departments also coordinated with federal chemists to pursue their goals (Goodwin, 2006).

Through these methods the groups were able to successfully disperse information throughout the country. This information was utilized in two main forms, consumer information and proof to push for policy. Armed with the knowledge of how dangerous patent medicines were, and the complete lack of regulation, consumers were able to avoid harmful patent medicines. Eventually, these women were able to court mainstream journalists and politicians to

pass the Pure Food and Drug Act of 1906, which established the FDA and required active ingredients to be labelled and confirmed via the Bureau of Chemistry.

Existing Studies on Vaccine Skeptic Movements

Several studies already exist pertaining to the effect of vaccine skeptic movements on public health, identification of characteristics of vaccine skeptic members, however almost all of the existing literature focuses solely on the consequences of the movement, and none treat it as a case study for how pharmaceutical activism movements can be utilized in order to successfully lobby public opinion to create beneficial regulatory and consumer environments (Dubé et al., 2014). This is a large gap within the research as the vaccine skeptic lobby has been one of the most successful at getting policy enacted (Carroll, 2021). There have been relatively few policies passed for supporters of movements such as reduced drug pricing, even though this arguably affects more people, and has a greater impact on those it does touch (Akhtar, 2021). In contrast, this paper proposes that one of the main causes of the vaccine skeptic movement's success is the characteristics of the publics that participate within it, specifically, the characteristics that allowed the pure drug crusaders to enact policy have allowed for the vaccine skeptic lobby to be successful as well.

Vaccine Skeptic Supporter Profiles

In order to collect data to guide comparisons between the historical movement of the pure drug crusaders and current vaccine skeptic movements, primary sources were sought in the form of one-on-one interviews with current members of the movement. In order to prevent any preconceived conclusions from being drawn, the subject guided the interview, and no specific subgroup was sought out. This allowed a natural framework to be founded upon and the

exploration of the idea of vaccine skeptics as a women's health movement similar to the pure drug crusaders without being tainted by preexisting literature.

Through familial connections, a owner of an alternative medicine practice in Ohio, with locations in rural Greenville, Ohio and urban Dayton, Ohio, was identified and agreed to interview. Secondly, a lyft driver who was a staunch vaccine skeptic supporter in Taberg, New York was identified by chance and agreed to an interview. Both of these individuals agreed to an interview, and both of them provided great insight into a truly diverse cross section of vaccine skeptic belief. Although a sample size of two is rather limited, both of them had customer facing positions that involved dialogue with a wide array of individuals. Further, states that are both traditionally Republican and Democrat were represented. Throughout the interviews the focus was on the causes that drove them towards their beliefs, the characteristics that defined them and other vaccine-skeptics that they interacted with, the methods that they utilized to attempt to convince others why vaccine-skepticism was a healthier manner of living, and the results that they had observed from their beliefs. Strikingly there were high levels of similarity between the pure drug crusaders of the 19th century, and vaccine skeptic supporters today.

Both women have surprisingly similar characteristics that they felt were key to their beliefs. Both had family members that had a more 'do it yourself' attitude in regards to health. Both had an inherent belief that it was up to the individual not a doctor to make yourself feel better as they had a distrust of the pharmaceutical system, specifically the application of medicines within the pharmaceutical system. Their distrust focused on the idea of consuming 'unnatural' products whose side effects were not well known, or were purposefully designed to be addictive. Both women had a belief that the average individual was capable of discerning truthful health information from false; however, neither woman had any process for discerning

what was truthful that they read beyond what ‘felt right’ and did not utilize any traditional form of fact verification such as peer review. This inability to methodically separate false information from true, played into an overall misunderstanding of science. When asked to explain the scientific underpinnings of the regulatory process neither interviewee could explain the system, further when asked about the COVID vaccine one interviewee stated patently false information that it would alter an individual’s DNA.

One key characteristic that both of the women felt was important was their status as a mother. The owner of the alternative medicine store in Ohio, had completely refused to ever take her daughter to the doctor, but would go herself, out of fear for her child. The Lyft driver, had initially decided to stop vaccinating after she believed her son developed autism from vaccination.

Outside of just these two women, they had observed several key characteristics, or perceived characteristics of fellow vaccine skeptics. Both women identified three main groups that participated in vaccine skeptic discussion, ‘white hippies and lower income people of color, and right-wing crusaders. The white hippies and right-wing crusaders, were identified to be more likely to completely oppose vaccination. White hippies, identified as affluent and politically liberal, were observed to have fallen off in popularity and had been replaced with the right-wing crusaders emboldened by Trump’s contrarian policies. Interestingly, the lower income people of color existed as a separate entity in terms of their vaccine beliefs, they were identified to be more likely to be skeptical of the COVID-19 vaccine but be more supportive of the rest of the pharmaceutical industry in general.

Such cross-cutting unified beliefs across economic classes, political affiliation, and race allow for a rather strong public group, this diversity in thought allows for greater lobbying across the political spectrum and means that most individuals probably know someone who is at the least skeptical of the COVID vaccine. This can be observed in the fact that while all 50 states allow for medical exemptions from public school vaccine requirements, 15 states currently allow for philosophical exemptions and only 6 do not have a stipulation allowing for religious exemptions (ProCon, 2020). Meanwhile similar popular movements such as preventing rising drug prices have not received such support, William Padula (2019) argues that a lack of a unified national front has caused this.

Movement Discussion and Comparison

The discrepancy between the success of the vaccine skeptic movement and the reasonable drug price movement highlights the need for an analysis of the characteristics of groups. As both groups receive reasonable amounts of support within the public, and the less successful one has wider public appeal. To do this an analysis and comparison of the vaccine skeptic movement to the

The point of motherhood plays into some of the key methods that vaccine skeptics utilize to lobby their agenda and recruit new members. The idea of a ‘mothers’ intuition’ allows for vaccine skeptic supporters to lobby their beliefs from behind a sort of political shield while simultaneously allowing for the recruitment of almost any familial unit, because about half of the population is physically capable of being a mother. Further the historical mom groups that were utilized during the 19th century pure drug crusade, have morphed into modern day social media mom groups. These social media groups have been utilized to target other mothers in being

recruited into vaccine skepticism. A prominent theme that arises within vaccine skeptic influencers on social media is the idea of a protective mother, and that by not vaccinating your children you are preventing them from being exposed to harmful chemicals. The idea of not protecting your child is inherently opposed to the classical idea of motherhood and drives these women to seek further information against vaccines (Baker & Walsh, 2022). In order to measure how harmful this search might be, I looked at the first results on Amazon for “Childhood Vaccine Safety” The first non-textbook or scientific journal was a vaccine skeptic book by the name of *Good-Bye Germ Theory* which states it is solely for parent’s education on the oppressive medical system, and how to challenge oppressive vaccination law (Trebing, 2006). These social media groups also target disenfranchised people of color, by highlighting the historical abuse of these groups by the pharmaceutical industry.

One of the key differences between the historical pure drug movement and vaccine skeptics in terms of their methods, is the rather heavy focus on rhetorical persuasion rather than scientific persuasion. The Departments of Science of the NWCTU (Goodwin, 2006) that advocated for scientific literacy and tested samples in order to determine dangerous ingredients in patent medicine have been replaced by questions and retorts like, *would you want to put anything unnatural in your body? If they won’t show you the statistics then you can’t trust them? If you can’t understand what happens to your body without joining in on their beliefs then it’s false! If you can’t pronounce it then it’s dangerous for your body!*

Interestingly, the vaccine skeptic movement does have its own version of The Departments of Science in the form of a laboratory of the individual. Vaccine skeptics adhere to their own beliefs of understanding what happens to their bodies by testing their own formulations on themselves. This allows for the classification of both groups as embodied health movements,

as they both have the defining characteristics of introducing the body to social movements by putting individuals and their experiences at the forefront; they both challenged existing scientific knowledge; and they actively collaborated in some form of science to pursue treatment.

These rhetorical questions are indicative of a general misunderstanding of science. Scientists are partially to blame, they historically have not been focused on public engagement, rather recognition in academia is the main measure of success. Many scientific communications over use jargon, and fail to correctly communicate to a lay audience the information that is desired to be conveyed (Kornei, 2021).

This inability to communicate also plays into the lack of successful scientific policy. This issue with risk perception however is a psychological issue, that is difficult to tackle, risk perception is utilized by the public for their beliefs rather than actual risk analysis as used by scientists and policy makers (Brown, 2014). As such two major lessons can be drawn, publics can be more responsive to rhetorical probing rather than scientific, and more persuasive scientific communication can solve some of these key issues.

Overall Scientists would greatly benefit from utilizing the characteristics and methods of communication of these successful movements to their advantage. Being able to adequately engage publics can be beneficial to the overall scientific system, and allow for more accurate leverage of the legal system through public lobbying of policy makers.

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