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[title] **Vaccine Rejecting Parents' Engagement With Expert Systems That Inform Vaccination Programs**

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Abstract In attempting to provide protection to individuals and communities, childhood immunization has benefits that far outweigh disease risks. However, some parents decide not to immunize their children with some or all vaccines for reasons including lack of trust in governments, health professionals, and vaccine manufacturers. This article employs a theoretical analysis of trust and distrust to explore how twenty-seven parents with a history of vaccine rejection in two Australian cities view the expert systems central to vaccination policy and practice. Our data show how perceptions of the profit motive generate distrust in the expert systems pertaining to vaccination. Our participants perceived that pharmaceutical companies had a pernicious influence over the systems driving vaccination: research, health professionals, and government. Accordingly, they saw vaccine recommendations in conflict with the interests of their child and “the system” underscored by malign intent, even if individual representatives of this system were not equally tainted. This perspective was common to parents who declined all vaccines and those who accepted some. We regard the differences between these parents—and indeed the differences between vaccine decliners and those whose Western medical epistemology informs reflexive trust—as arising from the internalization of countering views, which facilitates nuance.

Introduction

Childhood vaccination is one of public health’s salient achievements (Larson et al. 2014). Alongside environmental public health measures, it constitutes the most successful and cost effective global public health measure to reduce disease-related mortality (Andre et al. 2008). Like any medical intervention, vaccines can cause common minor side effects (e.g. fever) and very rare serious ones (e.g. Guillain-Barré syndrome) (ATAGI 2015). Accordingly, the immunization process induces complex decisions, both rational and emotional, in some parents faced with balancing the welfare of the community with a “do no harm” ethos for their own child.

While parental rejection of vaccines is complex and context-specific, varying across time, place, and vaccine (MacDonald and SAGE Working Group on Vaccine Hesitancy 2015), key themes recur in studies, with safety a predominating concern (Casiday et al. 2006; Mills et al. 2005; Smith et al. 2011). Other widely held concerns include the number of vaccinations and

perceptions they may overload the immune system (Hilton, Peticrew, and Hunt 2006). Some parents believe alternative medicines may suffice in place of vaccines (Zuzak et al. 2008), and some are unsure why their children still need to be vaccinated against diseases that are now rare (Janko 2012). Occasionally, parents may also recognize that if there is a high proportion of individuals who are already vaccinated, their own child can “hide in the herd” (Offit and Moser 2009).

Trust arises as an issue in numerous studies of why people do and do not vaccinate their children (Mills et al. 2005; Dube, Vivion, and MacDonald 2015; Yaqub et al. 2014), but the extent to which trust and distrust—as distinct concepts—shape vaccination decisions remains underexplored. In this study, we theoretically analyse trust and distrust to investigate parents’ perceptions of the expert systems central to vaccination policy and practice in Australia, where approximately 3.3 per cent of children are not up to date with their vaccinations due to their parent or caregiver’s active rejection of some or all vaccines (Beard et al. 2016).

We start with an important observation: trust and distrust are not binary categories whose qualities can be populated by the converse of the other. They are conceptually and semantically distinct from each other. Trust may be considered to fall somewhere on a spectrum between complete trust to complete distrust (Brown and Meyer 2015; Gambetta 1988). Distrust is often a focus of study; since distrust correlates with vaccine refusal, policymakers want to understand it in order to address it. Our work is situated in this realm. However, what trust and distrust share is that both are rooted in the cognitive (rational) and affective (emotional) and embedded in broader social contexts, health system understandings, socioeconomic structures, and illness vulnerability and chronology (Brown and Meyer 2015), as well as within health experiences and narratives. We follow a particular narrative here—that most of us appear to trust (for reasons relating to late modernity’s complexity), and some of us distrust (for reasons we further elucidate through empirical study). However, we do not suggest that the cognitive and affective drivers of vaccine refusers’ distrust are mirrored (in the opposite) by vaccine acceptors. We argue, on the contrary, that there are many pathways to the active acceptance of (as well as passive compliance with) vaccination, and trust need not be written on their signposts. When it comes to *distrust*, however, the strong relationship between distrust and refusal demands our attention, and is the focus of the present paper.

First, then, we explore “the rest of us,” in order to contextualize our analysis of vaccine refusers’ distrust. Given that the vast majority of parents in developed countries with access to childhood vaccines make use of them, one might deduce that these parents trust those who make, recommend, and administer them. Trust can be seen as a function to overcome the

uncertainties parents face in the decision to vaccinate, since informed medical decision-making requires that an individual grasps the condition and clinical context and has evaluated his or her preferences (Rimer et al. 2004, 1214). Complete knowledge is not always possible (or even perhaps desired) and therefore, accordingly, parents are called to place trust in healthcare providers to act in the interest of their child. Since providers are embedded within broader systems of service organization, professional expertise, and knowledge development (Mollering 2001; Mollering 2006; Luhmann 1979), trust extends to include health systems and broader social systems (e.g., economic, political, judicial) that shape knowledge and assumptions of health and healthcare (Luhmann 1995).

Conceptually, disentangling trust in individuals from trust in systems is challenging, since individuals (e.g. GPs, midwives) are seen to represent institutions and thus as “part” of them rather than distinct from them. Giddens (1990) refers to the “meeting places” for interpersonal and institutional trust as “access points”—the doctor for the medical system, the researcher for the scientific system, the politician for the political system, the news reporter for the media and so on.

Although everyone is aware that the real repository of trust is in the abstract system, rather than the individuals who in specific contexts “represent” it, access points carry a reminder that it is the flesh and blood people (who are potentially fallible) who are its operators. (Giddens 1990, 85)

According to this reasoning, we arrive at the centrality of both the individuals (“access points”) and institutions which together comprise *expert systems*. Expert systems penetrate nearly all aspects of social life in conditions of modernity (Giddens 1991; Habermas 1997; Scambler and Britten 2001). We trust in expert systems as a way of managing the limited technical knowledge that most of us possess about the information that routinely affects our lives (Giddens 1991). We need not have direct experience with that which we trust or distrust; social or cultural norms underpin the decision to trust and are based on a constructed characterization or stylized notion of the institution (Govier 1998). When we are faced with the uncertainty and risk central to health and medical decision-making, trust in expert systems reduces complexity; empirical research has demonstrated a “will to trust” that veils patients’ anxieties regarding a treatment or medical condition (Brown 2009).

Continuing with this narrative, a key marker of contemporary society is that trust can no longer be simply taken for granted or expected (Giddens 1994) and distrust (or at least healthy scepticism) has become the norm (Sztompka 1999, 6). To apply this reasoning to the present context, the bewildering array of individuals professing (or indeed holding) expertise

on vaccination in high income countries is in many ways emblematic of late modernity. Today, western medical epistemology is not the only system appealing to parents as a repository for their trust—alternative modalities also entice with critiques of that epistemology. Accordingly, parents choose “what” or “whom” they view as the expert system and, placing trust in that system, make the decision to vaccinate or not (Brownlie and Howson 2005). It is here that we can start to see the relationship between distrust in the dominant expert system and vaccine refusal.

Current literatures consistently link institutional distrust in government, pharmaceutical companies, healthcare professions, and medical science and technology to vaccine rejection (Dube, Vivion, and MacDonald 2015). In a British study, parents of under-vaccinated children found it difficult to know where to place their trust and did not trust the government (Austin et al. 2008). An American study identified trust as playing a key role in where parents were situated along the vaccine acceptance spectrum (Benin et al. 2006). Another found that parents who sought exemptions from vaccination were more likely than other parents to report “little or no trust in health information provided by ... government agencies, health provider groups or organizations and to distrust local doctors” (Gaudino and Robison 2012, 1135). Parents’ experiences with health professionals (“access points” of the vaccination expert system) are also significant, with insufficient, biased, poorly communicated advice from healthcare providers provoking distrust (Donovan and Bedford 2013).

Current social trends towards patient advocacy, empowerment, and choice are heightening some parents’ distrust in vaccines. While a conventional public health approach might concur with a Giddens-style (1994) narrative of an *erosion* of trust (“once we trusted, now we don’t”), we are cautioned by research on healthcare and trust to take a more critical view of compliance. Patients often follow the instruction of healthcare providers, not because they explicitly trust them but because they feel dependent upon them, particularly in high risk situations or when the public health system precludes choice (Ward et al. 2015). They may also feel obliged to follow directions—to “do as they’re told”—when these instructions come from government. This links to working class or specific culturally mediated notions of duty to the state (Ward, Coffey, and Meyer 2015). Such accounts of compliance remind us that we should not assume that the flipside of vaccine refusing parents’ reflexive distrust is a coherent and deeply held sense of trust experienced by the rest of us. Nor, indeed, can we nostalgically look back to a past where such a deeply held trust determined societal acceptance of vaccination. Lack of choice, lack of knowledge, and obedience to authority may explain this historical compliance as well.

Accordingly, it is more helpful to conceptualize a “contemporary health consciousness” (Crawford 2004, 50) driving many parents today to undertake protective action for their children. Protection from perceived risk of vaccines jostles against protection from disease. Parents pursue health information through unfiltered channels such as the Internet (Yaqub et al. 2014), which offers quick access and the advantages of interactivity, information tailoring and anonymity (Cline and Haynes 2001). Health information is one of the most frequently sought topics online (MuMullan 2006), with access growing rapidly through globalization, the diffusion of the news media, and social networking. Although moderated by other factors, information we encounter affects us—one study found that exposure to (what the authors described as) anti-vaccination conspiracy theories reduced the likelihood of intent to vaccinate (Jolley and Douglas 2014). When engaging with conflicting material it can be impossible to know the quality of the evidence chosen by those who assert knowledge. Brownlie and Howson (2005) argue that “when parents are identifying good reasons to either vaccinate or not, they are acting as bricoleurs, piecing together different knowledges” (226), a troublesome process because there are “good reasons” on both sides of the argument (224). In addition, current research identifies the role of social relationships and identities in vaccination decision-making, emphasizing that refusal is not simply a rejection of an offered benefit, but rather a process through which parents navigate social norms and articulate social inclusion and exclusion in relation to those around them (Sobo 2016).

The perceptions of members of this research team, as “experts” whose epistemological standpoint enables us to trust those whom *we* regard as experts, cannot negate the experiences of these parents whose knowledge is otherwise (socially) constructed. Accordingly, we take seriously our participants’ formulation of logic regarding vaccination even as they differ from our own assessments. While our approach privileges scientific knowledge, we acknowledge the body of literature critiquing evidence-based public health as being misappropriated by vested interests, lending support to calls for greater emphasis on lay experience and knowledge to guide policy and practice. Greenhalgh et al. (2014, 1) argue that the “evidence-based brand” is currently distorted as “the drug and medical devices industries increasingly set the research agenda” and “define what counts as a disease and pre-disease ‘risk states.’” Accordingly, critical reflection on the means by which knowledge (and our consequent labelling of “experts”) is constructed requires that we engage seriously with our participants’ questioning of the values underpinning Australia’s vaccination schedule and policies, and the interests being served, in order to better understand what informs their decision-making.

These considerations inform our analysis of Australian vaccine rejecting parents' construction of "what" or "whom" they trust and distrust when making decisions about vaccines. We asked questions about institutions with which we assumed they, as parents, would have direct experience in relation to childhood vaccinations. However, the parents may also be drawing from media representations and/or shared cultural values of the institutions, rather than direct experience. Our results and previous research (Gaudino and Robison 2012; Benin et al. 2006; Leask and Chapman 2002) depict competing expert systems at work, with allopathic healthcare (buttressed by scientific research, government and industry) challenged by the alternative epistemology of complementary and alternative medicine (CAM). Our aim is to understand what it is about allopathic healthcare—the expert system behind vaccination—that leads some parents to distrust both its "access points" (healthcare professionals in particular) and the system as a whole.

Methodology

We interviewed parents in Fremantle, Western Australia (WA) and Adelaide, South Australia (SA), who declined some or all vaccines for their children. Each recruitment site involved distinct research projects undertaken in different years but with convergent aims and methods sufficient to justify a pooling of data. Both studies aimed to better understand vaccine hesitancy; used a qualitative methodology with semi-structured interviews; and explored in-depth the underpinning perceptions of vaccinations, healthcare professionals, and social systems influencing the structure and function of immunization programmes. In Adelaide, interviews specifically sought to explore trust and distrust, while in Fremantle, interviews were conducted as part of a pro-vaccination campaign development and evaluation (Attwell and Freeman 2015). While each study explored these *a priori* interests, both focused on parental influences and experiences with vaccination expert systems. The qualitative in-depth interviews enabled us to provide rich accounts of the unique practices and experiences of each parent.

In Fremantle, parents were recruited between September 2013 and April 2014 from postcodes surrounding the City of Fremantle, which at the time recorded full vaccine coverage rates at below 87 per cent for children under five compared to the Australian average of just over 90 per cent (National Health Performance Authority 2014). Parents were recruited through posters, advertisements in the local newspapers, social media, and snowballing. Participants were screened prior to interviews to ensure that they met study inclusion criteria of delay or refusal of recommended vaccines and had a child aged five or under. In Adelaide, parents

were recruited between October and December 2015 from areas within postal codes identified as having low immunization coverage rates; less than the South Australian average 91.3 per cent at sixty to sixty-three months of age on the Australian Childhood Immunisation Register. Parents were recruited by the researcher at a suburban organic farmers' market and by snowballing, then screened to ensure that they met the study inclusion criteria of either delaying or refusing vaccination for their children. The University of Western Australia and Flinders University Social and Behavioural Research Ethics Committee provided ethical approval for the project under permit RA 4/1/5890 and project number 6976 respectively. To explore our participants' engagement with vaccination expert systems in late modernity, we applied deductive social theoretical reasoning (Willis et al. 2007) with a narrative analysis approach to our data. We worked from key principles of narrative analysis: recognizing overlapping stories from participants, interpretive explanations, and the future conclusions our readers would construct (Riessman 2008, 6). Lacking access to our participants' "unmediated experience," we were conscious of narratives constructed by "socially situated individuals" within the interview setting (23) and the impact of our interviewing, transcription, and analysis in the stories ultimately told (50). We focused on participants' interactions with the allopathic healthcare system and other systems and notions of trust and distrust. KA and PR interviewed participants face to face. Following transcription and narrative-reading, KA developed an initial coding tree using QSR International's NVivo 10 Software. This involved developing a visual representation of expert systems as constructed by participants. PW and JL evaluated a sub-set of the transcripts with continued input from PR, and the team agreed on a final coding structure based on the expert systems connected to vaccination policy and practice. During this process, personal reflection and open discussion during team meetings facilitated reflection on how our knowledge, experiences, beliefs, and backgrounds influenced our reading of the data.

Results

Semi-structured interviews were conducted with a total of twenty-seven parents: nine from Fremantle and eighteen from Adelaide. Twenty-four participants were women and three were men. Seventeen parents were aged between thirty-six and forty-two; the youngest was twenty-five and the oldest was fifty. The Fremantle parents were younger because of the age requirements of the youngest child. Over half of the parents had university qualifications. The sample included ten parents who had never vaccinated, five who commenced but ceased, seven who were currently delaying or partially vaccinating, and five former delayers now up

to date. We recognize differences between parents who decline all vaccines and those willing for their children to receive some or all vaccines eventually. However, in terms of how the participants in our study viewed the vaccination expert system, their fundamental perceptions were similar; for most it was only the strength of these perceptions that determined whether they could vaccinate despite their reservations. For some participants, the willingness to vaccinate despite their distrust developed over time, while for others the converse was true; their distrust of vaccinations increased as time progressed.

Unequivocally, parents' distrust specifically pertained to the pharmaceutical industry and the means by which it "infiltrated" other systems, thereby diminishing trust in allopathic healthcare. This concurs with Luhmann's (1979) theory of relational trust in social systems. In such a "web of trust" (Meyer et al. 2008), trust or distrust in one system impacts upon trust or distrust in others. As our parents described their interactions with, and perceptions of, the expert systems pertaining to childhood vaccination, their broad distrust of the pharmaceutical industry cast a shadow over other institutions and individuals. Everything, it seemed, was for sale, and this meant the parents could not trust the "experts."

Pharmaceutical Industry as "Puppet Master"

Our participants' distrust of the pharmaceutical industry (and the related systems in the "web") can be explained by their perception that it acts as a "puppet-master." Almost all our participants saw the pharmaceutical industry as the dominant force behind the expert systems pertaining to vaccination, "tainting" systems of research, the motives of health professionals, and the operation of government. Many framed this distrust of the pharmaceutical industry within a broader objection to capitalism. It is on this basis that we emphasize similar worldviews between those parents who outright declined all vaccines and those who, despite their dim view of the vested interests, factored in other considerations enabling them to accept some or all vaccines eventually. Almost all our participants depicted companies as responsible to shareholders rather than societies, with the profit motive itself suspect. Participants spontaneously linked the pharmaceutical industry to the resources sector, with its use of fracking; and agribusiness, with its use of genetic modification. "They don't care about us. It's all a big moneymaking scam and we are the cattle that is having money made off of us" (female, forty, SA, ceased vaccinator). Participants recounted events like those surrounding the pesticide DDT (dichlorodiphenyltrichloroethane) and the birth defects caused from the anti-nausea drug, thalidomide, in the 1950s and 1960s as part of what one called the "horrific history of the industry" (female, twenty-five, WA, partial vaccinator).

...[T]he whole pharmaceutical thing, to me it's just a big money making scheme... They're a business. They make money from people being sick, so they don't want to find a cure for this or that, because that means people won't rely on their drugs to help them get through their disease, or whatever it is that's making them sick. They want people to stay sick so that they keep buying their drugs, essentially (female, thirty-two, SA, non-vaccinator).

The pharmaceutical industry's untrustworthiness involved a perception of companies limiting information about risks and inefficacies. In explaining her distrust, the partial vaccinator above described "missing data, unpublished stuff when things don't turn out how they want them to turn out, the regulations around drug development and testing, and the information on that" (female, twenty-five, WA). Another participant referred to an alleged cover-up, "They're not going to advertise any negative about their stuff. They bury it. They go to great lengths to make sure that people don't actually see the negative effects" (male, forty-one, SA, non-vaccinator). The overall sentiment of most participants can be summed up thus: "Vaccines are run by Big Pharma companies; to me it's all about making money" (female, thirty-nine, SA, delayed vaccinator).

Rarely was this given a nuanced interpretation. However, the partial vaccinator who had only declined the varicella vaccine for her son rejected the notion that all pharmaceuticals were untrustworthy.

The notion that Big Pharma is only ever out to do evil is a bit naive and delusional. Is it evil to make money? ... [T]he Marxist in me probably thinks "Well, yes," but the pharmaceutical industry has developed drugs that treat cancer (female, twenty-five, WA, partial vaccinator).

Another was even more positive:

Look, a lot of people are pretty nasty about the pharmaceutical industry and they don't understand ... the research that goes into these drugs and the expenses and the costs and everything that happens, and they've got to make good money out of it once they get it. When you pay for a vaccine you're not actually paying for the production of the vaccine, you're paying for the twenty years of research and testing that went before it, so I don't have a problem with that' (female, forty-seven, SA, partial vaccinator).

The only other parent to be equanimous stated, "I don't trust them in certain areas, I guess. I do think they're all about making money, and clearly we've seen evidence of it, especially in the US, the way they're involved in politics, those companies ... " However, she went on to

reflect, “It’s a funny one, isn’t it, because obviously I trust them to a degree because I give my children medicines or immunisations that come from these companies ... ” (female, thirty-eight, SA, full but delayed vaccinator).

This last quote encapsulates the difference in degree between partial vaccinators and complete decliners. Partial vaccinators could “get on board” with vaccination to an extent, but still ultimately distrusted its agents on the basis of the pharmaceutical industry’s profit motive. Complete decliners’ more extreme perceptions ruled this out:

I see that the pharmaceutical companies ... were founded by war criminals from Nazi Germany and they were taken over to America and they started pharmaceutical companies. So are they practising Eugenics on us beyond our—like, without our knowledge? (female, forty, SA, ceased vaccinator).

Such distrust of the influence of the pharmaceutical industry was so pervasive that we now track it through the other systems of expert power that emerged from the interviews. We have adopted this approach because in seeking to answer the question: “What makes the vaccination expert system so untrustworthy for parents?” almost every road from the data led to the pharmaceutical industry. By illustrating exactly how the parents perceive its role, with tendrils curling into multiple facets of “expertise,” we can demonstrate how this expertise—the very expertise that we ourselves privilege as researchers—is contingent; socially constructed through cues to trust that do not reach all members of the public.

The Pharmaceutical Industry’s Influence on Research

Most participants were very suspicious of studies into vaccination, reflecting an assumption that all were funded by vaccine manufacturers and the results, or the dissemination of results, were biased by the profit motive. One respondent, who reported meticulous reading of numerous studies, complained, “Most research seems to be funded by pharmaceutical companies” (female, thirty-six, WA, unvaccinated). Another stated, “There is a lot of conflict of interest within the scientific field of vaccinations because the researchers have shares in outcomes so they only publish favourable outcomes” (female, forty, SA, ceased vaccinator). Participants were also concerned that comparative studies between vaccinated and unvaccinated populations, which might expose some of the risks they feared, would never be conducted.

You are not going to put a heap of money into something to prove something that is going to affect you negatively, and when you have got one kind of, like, main corporation, or a few corporations controlling everything; that’s what they do.

They are not going to do any kind of research ... (male, forty-one, SA, non-vaccinator)

Non-vaccinators are often accused of cherry-picking data to support stories of harm, cover-up, and collusion. However, our parents' accounts highlight two key concerns that cannot be so easily dismissed. The first concern is that funding of research does matter to perception. The political economy of university research—in particular the prevalence of researchers on “soft money”—renders researchers reliant on commercial funds (indeed, this is true of one of the studies in this paper). The second is that, given this political economy, certain research questions are unlikely to ever be asked, because even public money orients towards intervention-focused studies that can employ technocratic expertise in problem solving—with vaccine refusal a “problem” to be “solved.” This is the world with which we, as researchers, make accommodations, but those outside can perceive its limitations. They recognize, with an acuity not always recognized by “experts,” that researchers can pursue objectivity and neutrality but *research context* is anything but (Leach and Fairhead 2007, 23).

Pharmaceutical Companies' Influence over Doctors

Health professionals in general, and doctors in particular, also emerged as important “access points” for parents encountering the vaccination expert system. Participants were concerned about the access pharmaceutical companies had to influence doctors through presentations, “kickbacks,” and junkets, damaging their trustworthiness.

[Pharma] are a huge, billion dollar industry. Their shareholders want to make a profit ... they're giving doctors world class, first class flights to somewhere all over the world. If they sell enough of their drug, we will fly you first class, and your wife, to a lecture on this drug. (Female, thirty-nine, SA, non-vaccinator)

Participants perceived this financial reach stretching right back to doctors' training.

The pharmaceutical companies supply the universities with funding ... so it comes down to the doctors that have, you know, their information that they have and ... their scope of operation comes from their training which is funded by, you know. They have got a certain way of being taught and that's it. (Male, forty-one, SA, non-vaccinator)

These data point broadly to the perception of collusion between the pharmaceutical industry and medical professionals, whereby doctors may recommend vaccines that conflict with the interests of the recipient. However, one participant noted, “I have quite a few family members in the medical community, and I find the complete distrust of medical community

to be offensive, really...” (female, twenty-five, WA, partial vaccinator). This participant’s personal connection to medical professionals she regarded as trustworthy appeared to influence her perception, though she immediately followed this statement with an unsolicited declaration of distrust in drug companies. We will return to the significance of this later.

The Pharmaceutical Industry’s Influence over Government and Bureaucracy

A particular concern for participants was the influence of pharmaceutical companies over the state. It was in these responses, in particular, that the perception of the pharmaceutical industry as ultimate “puppet-master” became clear. The participant who described doctors’ “junkets” went on to question (rhetorically), “What are they [the pharmaceutical industry] doing to the government?” She queried whether advisors who help Parliamentarians make decisions were paid or biased (female, thirty-nine, SA, non-vaccinator). Another declared outright: “I think that they [the pharmaceutical industry] own the government” (female, forty, SA, non-vaccinator), and a third stated, “[T]he leaders of the government actually have shares in the pharmaceutical companies that these vaccines represent, so it’s a very big conflict of interest” (female, thirty-six, SA, non-vaccinator).

Participants saw the pharmaceutical industry’s government influence playing out in two key ways. First, through the technocratic decisions of highly specialized bureaucrats and advisors who compile the vaccination schedule. Participants were suspicious that the large number of vaccines on the schedule was driven by profit. Even the participant who was most equanimous about the industry’s morality, “wonder[ed] about over immunisation, if it is really about moneymaking” (female, twenty-five, WA, partial vaccinator).

Concerns about the schedule also contributed to broader fears of government power, informed by vested interests:

[T]hey’re bringing out all these schedules and all this stuff and it’s like, “Give us a break.” ... I don’t trust these people to—you know, because it’s all interlinked with the power of government and the agendas. (Male, fifty, SA, non-vaccinator)

Second, participants perceived pharmaceutical companies’ reach in governments’ use of policy levers to coerce parents to vaccinate. After the WA data collection, the Australian Federal Government initiated a more “hard line” policy towards vaccine exemptions. “No Job No Pay” withholds access to financial benefits, including childcare subsidies, from those who decline vaccines by removing a previously available “conscientious objection” (Parliament of Australia 2015). South Australian respondents interviewed after the policy change responded

strongly to it. More than one queried its logic, given that the small numbers of parents affected would not produce savings for the government. Rather, it was a matter of control:

It's just knowing that the pharmaceutical companies have got such a strong hold on the government that they make those kinds of decisions ... [The government are] not going to benefit [financially] ... so the only reason I can see for them doing it is the pharmaceutical companies are taking a stronger hold on our lives. (Female, forty-two, SA, non-vaccinator)

This participant continued that she did not see every politician as implicated in “individually think[ing] about it.” Rather, “there are much higher levels in the government and higher people who are pulling the strings.” “Ultimately,” concluded another participant, “money drives decisions” (male, forty-one, SA, non-vaccinator).

Another participant elaborated how she saw this policy change playing out:

I feel like the pharmaceutical company is getting ... a huge say in ... how the government chooses to go with those things and if they are going to get a lot of money ... or there is going to be a payoff for certain things. I believe that that is also an issue. I think there is a, you know, underhanded deals that, “Yeah, let's make it so they all have to do it now.” (Female, forty-two, SA, non-vaccinator)

Construction of Consensus

Part of the role of the pharmaceutical industry as puppet-master was its capacity to construct and sustain ideological hegemony with regard to vaccination in broader society, through sheer financial muscle.

I just always wondered about the power of the pharmaceutical companies and the people who make money out of this and the huge power they might have in—which would be a pretty big opponent for people who had other ideas. I could see that just being a very scary environment to step into and present any other ideas or any other research, even. (Female, thirty-nine, SA, delayed vaccinator)

The media was part of this picture for respondents who presented a web of profiteering relationships between pharmaceutical companies, magnates, and the government:

... When you see things like Rupert Murdoch [owner of many Australian newspapers] was friends with Tony Abbott [Prime Minister at the time] and Rupert Murdoch's son sits on the board of GlaxoSmithKline [pharmaceutical company producing vaccines], it just doesn't—you know, your mind goes “Why? Why are you doing this?” (Female, fifty, SA, non-vaccinator)

Other Features of Expert Systems

Although the dominance of the pharmaceutical industry was the clearest theme to emerge from the research, participants described other quasi-malignant features of the expert systems they had encountered on their (non)vaccination journeys. Several participants used “the system” in their discussion of Western medicine, and one-sidedness, authoritarianism, and rigidity were its key perceived failings, echoing other studies (Brown et al. 2010). Many distrusted Western medicine because they saw it as narrow, symptom-focused (with links back to pharmaceutical companies) and the opposite of holistic. Often, perceptions related to negative experiences with specific health providers, highlighting again how “access points” are central to perceptions of institutions as a whole—in this case the entire institution of Western medicine.

Discussion

Our study found that the discourse of parents who reject vaccines is dominated with notions of the pharmaceutical industry and the profit motive. This finding echoes those of a number of other studies (Sobo 2015; Benin et al. 2006; Brownlie and Howson 2005). The parents we interviewed saw the pharmaceutical industry as exerting a wide-ranging influence on vaccination research, the motives of health professionals, and the construction of government policy consensus. This discourse was readily mobilized in their rationale for their vaccination decisions.

There was a general lack of specificity regarding the agencies and mechanisms through which industry explicitly influenced vaccination policy, although we did not probe for this. We could draw one of two conclusions. Suspicion of the pharmaceutical industry may indeed form a genuine basis for decision-making, but it possibly also serves as a salient post-hoc rationale within a mainstream Australian framing of non-vaccination as deviant. However, the parents in both Fremantle and Adelaide were actively choosing alternative lifestyles—eating organic food and utilizing alternative healthcare and education. A distrust in big business to look after the concerns of the public—coined the Greedy Bastard Hypothesis by Graham Scambler (2001)—is indicative of a left-wing ideology and “off the grid” philosophy. Rejecting capitalism would fit with our parents’ *Habitus* and their social identities, with vaccine refusal in valued social settings generating bonds and affirmation (Sobo et al. 2016). Accordingly, we take seriously the parents’ representations of the

pharmaceutical industry as a significant driver of the distrust that induces vaccine refusal, and recognize its socio-political elements.

Our study demonstrates that perceptions of expertise with regard to vaccination are socially constructed, and that judgements of whom or what is trustworthy arise in specific contexts that may facilitate or block the development of trust. We learn from our participants to look to our own social contexts and methods of reasoning, and to ask ourselves how we differ from them in our acceptance of childhood vaccination programs as a public good. Analysing these differences serves two purposes. First, it reminds us to focus on what it actually means to “trust the experts,” something we might otherwise gloss over, given the consensus, at least within our research team, to consciously and reflexively trust expert systems with regard to vaccination. (We do not assume that such trust is a driving factor for the rest of the vaccinating population, since they may be motivated by other factors.) Second, distrust in vaccination can manifest in a “public bad,” with refusal correlating with outbreaks of preventable disease (see Omer et al. 2008). Since the political economy of research inevitably draws us to considering technocratic responses to this “public bad” (to restore the “public good” of herd immunity), it is useful to assess whether interventions address how these parents differ from those who reflexively “trust the experts.”

To engage in this comparison, we first return to the political economy of research itself, and our intimacy with government, the public sector, and vaccine manufacturers, as researchers (and sometimes advocates) addressing non-vaccination. As researchers, we are familiar with both the objectivity of the research process *and* the political and economic drivers of the research we do. Our intimacy with research (including the meaning of systematic reviews, the distinction between correlation and causation and the synthesis of numerous methods to arrive at the same result) provides some of the basis for our trust.

Second, we can enhance the comparison between those who trust and those who do not by returning to the distinction between partial vaccinators and complete non-vaccinators. As we noted above, the parents who ultimately consented to some vaccinations still distrusted the industry and its profit motive and did not follow the schedule on this basis. Their acceptance of some vaccines, however, demonstrates mitigation of this distrust with other factors, such that they came to be sufficiently comfortable with nuance. The pharmaceutical industry remained untrustworthy, with its tendrils infiltrating research, medical professionals, and government negatively, yet parents incorporated contradictory beliefs into their assessments. Pharmaceutical companies make drugs that treat cancer. There are good and trustworthy doctors. Parents accept vaccines despite their distrust.

We suggest, then, that ultimately the difference between those who trust “enough” to vaccinate and those who do not, is the absolutism of the worldview that the profit motive facilitates only bad. Here, absolutism is not only the strength of the belief; but also the extent to which it is untempered by other considerations, the comprehension of complexity, and sitting with dissonance. It may not be possible to counter all-encompassing worldviews of corporations that seek to profit through harm—inducting and corrupting governance and healthcare in their mission—head on. One possible answer derives from our reflections on how we and some of our research participants arrive at nuance, supported by research that shows selectively vaccinating parents oscillate between numerous standpoints and tend towards indeterminate positions on vaccination (Sobo et al. 2016). We should avoid attempts to drastically re-orient worldviews, given that those initiating them would be distrusted anyway. Instead, we could creatively develop ways of priming for nuance, capacity building for dissonance, and sharing our own insights into how we see what the parents see, but see it differently from inside the system. Additionally, we need to explore mechanisms for increasing trust and consider whether the expert systems under study in this article can do better in this regard.

Conclusion

Our actively non-vaccinating parents conveyed a perception of vaccination expert systems as tainted by the profit motive of pharmaceutical companies. This “taint” linked to broader anti-capitalist critiques of big business, with parents perceiving the pharmaceutical industry’s reach over research, doctors, governance, and society. With reflection on our own relationship to the vaccination expert system, we suggest that degrees of distrust appear to be determined by the incorporation of countering views. Accordingly, one set of strategies to address the deep distrust that provokes vaccine refusal could involve openly acknowledging the pharmaceutical industry’s sometimes pernicious role, while sharing experiences and perspectives to facilitate nuanced views that can sit alongside it.

Competing Interests

See under “Funding.”

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