Risk, responsibility and negative responses: a qualitative study of parental trust in childhood vaccinations

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Abstract

Aims - Childhood vaccination programs have benefits that far outweigh risks, in public health terms. However, some parents decide not to immunise their children. This paper explores the ways in which such parents talk about the perceived risks and benefits incurred by vaccinating (or not vaccinating) their children.

Methods – Between 2013-2016 we undertook 29 in-depth interviews with non-vaccinating and/or ‘vaccine hesitant’ parents in Fremantle, Western Australia and Adelaide, South Australia. Our analysis of the interviews identified particular constructions of risk and responsibility. All interviews were transcribed and analysed using both inductive and deductive processes.

Findings – Our analysis mirrors the chronological process through which parents navigate risk. We start with the concept of ‘responsibilisation’, which underpins parental engagement with decision making and praxis. We then explore how responsibilisation takes the form of detailed and time-consuming ‘research’. Parents then attempt to navigate multiple and conflicting ‘risks’: the risk of vaccine preventable diseases, risks associated with vaccination, risks associated with their own perceived lack of understanding. After engaging with risk, parents justify the decision and accept the associated ‘responsibility’. Parents use this sense of responsibility to navigate through the ‘responses’ of others, which we conceptualise as the risk of unwelcome consequences.

Conclusion – Parents have a reflexive understanding of the physical, psychological and socio-economic risks they incur as a consequence of their choice to either partially vaccinate, delay vaccination or reject vaccination for their children. They construct these risks with reference to particular discourses, engagement with expert opinion and lifestyle choices emblematic of late modernity. The risks they are willing to accept, and the subsequent responsibility and blame they assume when choosing to abstain, or partially abstain, from vaccinating their children are, to the parents, coherent with their interpretation of best parenting practice.
**Introduction**

Interest in understanding vaccine hesitancy and vaccine rejection has surged in the past decade. Public confidence in the safety and efficacy of immunisation programs has waned in some countries (Dubé et al. 2016, Dubé et al. 2015), manifesting in increased rates of selective or delayed vaccination (Omer et al. 2012) or a decrease in acceptance and coverage for certain vaccines (Amendola et al. 2015). At the height of the UK’s unfounded MMR vaccine scare, 74.4% of parents whose children were unimmunised said they had made a conscious decision to reject the vaccine (Pearce et al. 2008). At the same time, the use of personal belief and religious exemptions accelerated in the US, in particular between 2005 and 2011 (Omer et al. 2012). In Japan, uptake of HPV vaccination declined sharply after unfounded safety scares (Hanley et al. 2015).

Parents who choose to partially or wholly reject vaccines do so on the basis of complex and deeply-held belief structures (Brown et al. 2010), which are difficult to change (Kreuter and McClure 2004, Grimes 2016, Nyhan and Reifler 2015, Nyhan et al. 2014) and include safety concerns, mistrust, preference for alternative medicine, and arguments for civil rights (Reiss and Weithorn 2015, Lee et al. 2016, Sobo 2016b, a). The decision to reject vaccines must be read as a feature of an increasingly complex world in which the right to choose has become both a broad cultural expectation as a citizen (Aldridge 2003, Gabe and Calnan 2000, Brown, Baker, and Ebooks 2012, Kaufman 2010). Since both vaccination and vaccine rejection pose risks, perceptions of risk play an ever important role in shaping parental decisions. Beck argued that risk need to be understood as a product of social processes, as opposed to an abstract ‘thing’ that sits outside of such processes, “The world is not as it is; rather its existence and its future depend on decisions [emphasis in original]” (Beck 2009) (p. 4). This paper draws on such a sociological understanding of risk in order to explore the perceptions of risk and responsibility by parents who made decisions to reject some or all vaccines for their children.

In the ever-growing swathe of literature on parental vaccine hesitancy and refusal, risk recurs as a central theme. At the turn of the century, as parental vaccine refusal became a subject of concern for researchers and public health authorities, literature reflected assumptions that parents were making rational cost-benefit
analyses as they evaluated risk, but with little to no evidence (given the limited research) that such risk framings were indeed underscoring how parents approached vaccination (Hobson-West 2003). From within this paradigm, the concern with the risk assessment process – and its apparent path to vaccine refusal – was that parents had insufficient information about vaccines, community immunity and vaccine preventable diseases (VPDs). The traditional health-education logic followed that more information would therefore enable parents to make more effective (and realistic) risk calculations, leading them to vaccinate. This was linked to the now discredited “deficit model” (Leask 2011, Hobson-West 2003), which assumed that an information deficit drove vaccine rejection, and could be addressed by filling-up parents with appropriate information to inform rational decision-making – engaging with parents as so-called ‘docile bodies’ outlined by Foucault (1977, 1989) and taken on by others (Williams 2003). Kata (2010) argues that “Traditional controversy dynamics, with “audiences” needing to be “educated” by “experts”, no longer apply” (p. 1715).

The deficit model is mirrored in common evaluations of lay perceptions of risk – ‘real’ risk as defined technically (e.g. epidemiological risk of vaccine side-effects), and ‘subjective’ risk (or ‘feeling of risk’ (Slovic 2010, Slovic et al. 2004, Betsch et al. 2010)) as perceived by lay people, sitting alongside the binary expert/lay distinction (Beck 2009). Using this distinction, Beck argues that ‘real’ risks are often used as the societally accepted yardstick to make appropriate decisions, and lay people are seen to require ‘risk literacy’ in order for them to understand the ‘real’ risks and thus make decisions based on science, rather than subjectivity (p. 12). However, (any) risk can only exist as part of human understanding:

“Risks do not have any abstract existence in themselves. They acquire reality…. The notion of an objective yardstick against which degrees of risk can be measured overlooks the fact that risks count as urgent, threatening and real or as negligible and unreal only [emphasis added] as a result of particular cultural perceptions and evaluations” (Beck 2009 p. 13).

Here, we reject the deficit model and the real/subjective risk binary, on the basis that they ignore how and why parents make (for them) appropriate and logical assessments and decisions in social contexts (Kata 2010, Kahan 2014, Attwell et al. 2017, Leask et al. 2006). Indeed, in order to affect behaviour change, we need to understand and work within the ‘moral position’ of the population of interest, otherwise we simply place them in a deficit position (Feinberg and Willer 2015), as has been found in numerous psychological experiments (Nyhan and Reifler 2015, Nyhan et al. 2014, Betsch et al. 2010).
In recent times, attention has turned to the role of heuristics in the shaping of decisions (Zimmerman et al. 2005), including risk evaluations (Smith, Appleton, and MacDonald 2013). A recent study found that hesitant parents perceived the risks of both vaccination and VPDs as ambiguous, and did not mention any evidence-based material they may have seen previously; consequently they constructed “risk perceptions and mental models … plausible and meaningful to them” (Blaisdell et al. 2016). This included personalising vaccine risks and framing vaccine harms as permanent and severe, whereas they regarded themselves to have capacity to reduce disease exposure and poor outcomes (Blaisdell et al. 2016) (p.484) This ‘psychological turn’ in considering vaccine refusal links to behavioural theorists reconceptualising humans as non-rational actors (Thaler and Sunstein 2008). This approach coexists today alongside ever more nuanced studies of parents making subjective risk decisions in social contexts. Brown (2011) (p.143) introduced the idea of ‘redundant risk’ to explain how parents feel damned either way – conflicting information and overwhelming access to information makes it “possible to perceive all available courses of action as potentially hazardous”. Indeed, Beck argues that having more knowledge about risk actually increases perceptions of risk (Beck 1992, Beck 2009).

As will be come clear within this paper, we argue that contemporary vaccine refusing parents see engagement with risk assessments as part of the requisite practice of questioning vaccines, undertaken as part of their vigilance in late modernity. In line with this argument that such parents make conscious and active risk assessments, Kaufman argues that parents have become ‘subjects of freedom’(Kaufman 2010) (p. 12). In this way, parents are required to understand risks, make decisions and live life in terms of personal choice, “through the right to and problem of choice in the face of risk and indeterminacy” (Kaufman 2010a, p. 22). Indeed, Kaufman argues that a failure to look after the self and children is seen as a moral transgression - people are impelled into a project of the self (and their children). This process has also been conceptualised as responsibilisation (Fane and Ward 2016, Foucault 1991), whereby responsibility for certain functions which were formerly provided by the State are taken on by individuals. These parents have been responsibilised to see vaccination not as a given (i.e. something they feel they have to do because the State advises it, like a ‘risk contract’ (Beck 2009) (p. 7)), but as an individual choice and decision. Such responsibilisation can be State-initiated through broader patterns of civic and political (dis)engagement
(Brown, Baker, and Ebooks 2012), with an unintended consequence being that some individuals end up rejecting the broader aims or mandates of State policies, such as public health. However, some people actively want to take back control (often because they do not trust the State in that context) and trust themselves to perform the tasks, thereby moving the responsibility from the State to themselves (Lehrer 1997).

From a technical science perspective, one could see the decision not to vaccinate as a form of resistance to science, often constructed in derogatory, negative and risk averse terms. However, Bauer (2015) argues that resistance to science is “logically and empirically a corollary of choice” (p. 5). In defence of resistance and what he terms ‘resistology’, he argues that scapegoating of resistance “is based on strange assumptions, namely the new is necessary and always superior to the old” (p. 5). Nevertheless, the consensus of scientific knowledge and opinion would argue that the potential consequences of parents actively choosing not to vaccinate their child/ren is far riskier than choosing to vaccinate, thereby non-vaccinators place their children at risk and spreading VPDs to vulnerable populations. Consequently, vaccine refusing parents have often been framed in the popular media as being ignorant, irresponsible and selfish (Harvey 2015b). Brown et al.’ (2012) found that parents who rejected the MMR vaccine compared their decision-making rationales with those of other parents, assuming their own decisions would be judged by fellow parents, family, friends and health professionals. Expressing a sense of personal responsibility, they anticipated guilt and shame from others in their family and/or community if their choices turned out badly. Vaccine decision-making is a factor on which “responsible parenting, morals, and perhaps even intellect” can be judged (Brown et al. 2012)(p. 1859). We consciously consider this in the framing of risk in this paper. We emphasise that vaccine questioning or refusing parents are acting in what they see as the best interests of their children and consequently, as custodians of their children’s health, assume the risks for the decisions they make.

Methods and data analysis

Vaccination resistance is argued to encompass both individual and collective perceptions of risk (Berezin and Eads 2016), thereby requiring qualitative research methods which can tap into such narratives. Here we
describe a study of parents who do not vaccinate or hesitate to do so. A detailed description of the methods and analysis used in this study has been provided in another publication by the research team (Attwell et al. 2017) but a shortened description is provided here. Parents were recruited from two Australian cities: Fremantle, Western Australia and Adelaide, South Australia. Interviews were conducted with parents who had not vaccinated, partially vaccinated or delayed some vaccinations for their children. Within the interviews, we focused specifically on routine recommended vaccines on the National Immunisation Program which are provided free of charge. Data were extracted from the collation of two research projects, which although were conducted in different years and in different Australian States, had sufficient similarity in their methodologies and study aims to enable the resultant datasets to be merged. Both studies used an interpretative, qualitative, methodological approach; undertaking semi-structured interviews to better understand parental vaccine hesitancy. Adelaide interviews were conducted between October and December 2015 with parents residing in areas with whose postal code was identified as having low immunisation coverage rates. Parents were recruited by the researcher at a suburban organic community market and by snowballing, and screened to ensure that they met the study inclusion criteria. Fremantle parents were interviewed between September 2013 and April 2014, drawn from postcodes surrounding the City of Fremantle, which also had low immunisation rates. Fremantle 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 the study inclusion criteria. Interviews for both studies attempted to understand, from the parental perspective, the various reasons why they decided not to (or partially) vaccinate their children. Flinders University Social and Behavioural Research Ethics Committee and The University of Western Australia provided ethical approvals for the projects, under project number 6976 and permit RA 4/1/5890 respectively.

‘A potentially important context is a safety issue related to one brand of a trivalent influenza vaccine given to children in 2010 with very wide distribution in WA in particular. This vaccine was temporarily suspended due to a spike in reports of febrile convulsions among children aged under 5 years. Government resumed its recommendation for all but one brand, but there was a persistent decline in influenza vaccine uptake for children in Western Australia (Blyth et al. 2014). It is likely that this event would further contribute to reduced trust among the already skeptical, in all states but particularly in WA because of the wide promotion then suspension of the vaccine and that the parents of one child reported to be brain injured after a febrile convolution from the vaccine public in their quest for compensation (King and Leask 2017).
In total, 29 parents were interviewed, 9 from Fremantle (interviewed by KA), 20 from Adelaide (interviewed by PR). The majority were women (n=25). The age range of parents was 25-50 years; 19 were aged between 36 and 42. Fremantle parents were younger due to the age requirements of the youngest child. Over half of the parents held a university qualification. The participants included 12 parents who had never vaccinated their child(ren), 5 who had commenced but ceased, 7 who were currently delaying or partially vaccinating, and 5 parents who had previously delayed, but who were now up-to-date.

The interviews were transcribed verbatim and coded and analysed in NVivo 10. Three stages of analysis were undertaken: coding, conceptual categorisation and theoretical categorisation, explained in more detail elsewhere (Attwell et al. 2017). When the data were coded, words, or sections of text were ‘named’ using the actual words used by participants or by grouping similar words conceptually. Coding of a selection of transcripts was undertaken separately by PW, KA, JL, and PR in order to develop a shared and agreed coding framework. The initial selection of transcripts represented a cross-section of the interviewees in both localities. Conceptual categorisation was undertaken by grouping the initial codes into larger categories. This process involved an iterative process of inserting each of the initial codes into larger categories, based on their ‘semantic fit’ or the ways in which they seemed to be relating to a similar idea or issue. We examined the focused codes with respect to the theoretical and empirical literature on risk and responsibility. This process highlighted data that both conformed to current theories and ‘new insights’. In particular, the researchers explored differences and similarities between participants with different histories of vaccinating their children, some of whom originally vaccinated but now do not and some of whom have never vaccinated their children. Frequent discussions within the research team validated emerging codes.

**Results and Discussion**

We have organised our results using a series of “R” headings that demonstrate the chronological process through which parents navigate risk with regard to vaccine acceptance and refusal.

**Responsibilisation**
What it means to be a healthcare consumer and a parent – and indeed what it means to be human – has undergone dramatic transformation in the last century. As noted above, the rolling back of the welfare state, which had been responsible for constructing and delivering public health to citizen-subjects, has led to a re-imagining of subjectivity. Scholars of health and public policy employ the Foucauldian concept of ‘responsibilisation’ (Foucault 1977, 1989, 1991) to explain how the state governs today’s subjects at arm’s length, exhorting us to take responsibility for our own life trajectories and holding us accountable when we fail (Brown, Baker, and Ebooks 2012). Parental vaccination questioning and refusal occurs within this framework; ‘the individual is morally responsible for health … parents reflexively practice and ponder an ethic of care and choice in relation to how they think about the risk of vaccines (Kaufman 2010) (p.12).

Being a blind follower of the state, or “doctor knows best,” is inconsistent with this contemporary trend towards agency and responsibility. This played out for the parents in our study as an explicit recognition that it is their responsibility, first and foremost, to navigate and make decisions regarding vaccination. The self-trust herein is evident. Meg (WA) said, “I know the government is probably panicking going ‘this child hasn’t been immunised’ and I’m like, leave me alone, I’m not an idiot. I am not going to risk my child. When they are both going to be closer to the risky age, then I will sort it. I’m intelligent, you know, I have brain of my own. I can work it out.”

The decision whether (or not) to vaccinate is merely a part of a broader project of pursuing a professionalised, highly considered and labour intensive parenting practice we call salutogenic parenting. Salutogenic parenting is an enactment of responsibilisation, with parents demonstrating a high level of agency in ensuring their child’s development, well-being and health (Hays 1996). Most parents in this study adhered to a salutogenic parenting pathway including eating organic food; reducing the ingestion of, and exposure to, chemicals in their environment; limiting children’s time on ‘screens’, and encouraging physical and emotional development through creative play. A similar type of salutogenesis has recently been found with parents of children at Waldorf (Steiner) schools in the US, who also have a much lower rate of childhood vaccinations (Sobo 2015b, a). A similar concept of ‘concerted cultivation’ (Lareau 2011) has been used to describe complex parenting practices aimed at protecting children from risk. However, our data
show that parents’ primary focus was on developing and maintaining health and wellbeing in their children (assets-based) more than purely protecting them from (negatively-framed) risks.

Holly described this lifestyle: “[W]e use very minimal chemicals, the same as in our cooking. We have the organic fruit and vegetables wherever possible, drink filtered water, things like that. I guess our whole lifestyle, we make sure we’re moving. We’re not a sedentary family sitting in front of the TV, we’re out in the garden, we’re growing our own food…I look at the whole picture of the organism”.

As we discuss subsequently, salutogenic parenting became a further method of enacting responsibility for the individual and social consequences of some participants’ vaccine refusal.

Research

Responsibilised parents ‘do their research.’ All the parents in this study talked about the investigations they undertook in order to make decisions about vaccinating (or not vaccinating) their children. These included: reading information; talking with health care professionals and friends/family; and searching for information online (on academic databases such as PubMed, generic search engines such as Google and various social media platforms). Similar patterns of information searching have been found in other studies (Sobo et al. 2016, Kata 2010, Leask et al. 2006), although scholars have found that parents also focus more on localised risk perception models (Blaisdell et al. 2016). Our participants discussed weighing up the relative risks and benefits of vaccinations. They talked about trusting their own abilities to search for relevant information, their trust in what they found, and their ability to analyse the information and make appropriate decisions. Luhmann argues that such self-trust is linked to people being comfortable taking on personal responsibility for their decisions (Luhmann 2000).

Many parents stated that their decisions not to vaccinate their children were not easily made, and that attempting to interpret the risks and benefits gleaned from various information sources often led to uncertainty, confusion and a sense of anxiety. Owen (SA) found it almost overwhelming, especially given his view (shared with many other parents) that the government just wants people to vaccinate in the absence
of fully informed choices. The difficulty of making decisions with conflicting and contradictory information was made more difficult, since most non-vaccinating parents (including Owen) had an enduring sense of distrust in the government and the pharmaceutical industry (Attwell et al. 2017). As Kavita (SA) said (in a joking, sarcastic manner), “you do want to believe the government has your best interests at heart... that the government’s doing the best by us. There’s no conspiracy. The media’s just telling us the right things... and what the television stations are actually trying to tell us and what Big Food is actually putting into our food and what Big Pharma is actually trying to put into our systems”. Later, Kavita (SA) talked about actively grappling with conflicting interpretations of information provided by ‘science’ and ‘non-science’ sources, making it very difficult to make decisions. “Science says this, the non-science stuff says this. You can read an article about herd immunity, but then you can read the interpretation of that article by someone who doesn’t believe in herd immunity and they can break up everything that’s been said. It just makes you really, really confused”. This concurs with research in the US that found that “vaccine anxieties may not result from objections to particular policies or institutions, but from the debate’s back-and-forth antagonism that likely contributes to suspicions of “expert systems’” (Kata 2010) (p. 1715). Ultimately, Kavita’s lack of trust in science and government made her comfortable with her decision not to vaccinate her child, even amidst some uncertainty, because the risks of vaccination outweighed the possible benefits for her. She practiced salutogenic parenting which further diminished the perceived need for vaccinations.

Risk Assessments

Armed with information gathered during the research process, our responsibilised parents engaged in risk evaluations in which they explored the various facets and consequences of potential vaccination decisions. The risk of vaccines was clearly the most pressing issue for parents, and they were often preoccupied with this as an absolute risk. For example, Clara (WA) explained her decision to delay her daughter’s vaccination thus: “[E]ven though I know the risk is minute, if I waited until she was two and gave her lots of vitamin C beforehand... I had to make this risk as small as possible for me”. A recent US report and systematic review recommend that scientists and healthcare professionals need to communicate both relative and absolute risks more effectively in order to improve parental knowledge and vaccination rates (Institute of Medicine 2013,
Maglione et al. 2014). While communicating risk well is good practice, it falls into the ‘deficit model’ trap, if getting ‘our’ knowledge across ‘better’ dominates efforts. As already noted (Feinberg and Willer 2015), we need to understand the moral and epistemological position of parents and order to communicate in a more socially appropriate way, hopefully engendering trust and reciprocity.

For parents assessing vaccine risk, the risk of disease was clearly waiting on the opposing arm of the scales, also demanding consideration. Tabitha (WA) talked about how relative risks of her child contracting different possible diseases affected her calculations on which vaccinations to accept, and when. “[T]he decision was to do a delayed schedule with [child’s name], and then to immunise him first with the things we felt were most threatening. And then with the least threatening at the end… [F]irst was whooping cough, which… as you know is epidemic around here. And then the least important at the time was hep B. So we still haven’t completed hep B”.

Most parents talked about the uncertainties embedded in an epidemiological framing of risk factors (e.g. 1:10,000 risk), which communicators often employ to show that vaccines are far less risky than VPDs. The parents remained ultimately unconvinced, both in terms of the risk of contracting an illness and the risk of an adverse reaction from receiving a vaccination. In part, this was because population-level framing does not resonate well when parents any risk to their own child as unacceptable. For example, although Meg (WA) recognised that the risks of her child contracting a major communicable disease might be low, she did not want her child to be “that one in 500 billion.” The difficulties in interpreting risk information created some differences in how parents then interpreted the risks for ‘their’ child. Pippa (SA) talked about her sense of relativist or ‘on balance risks’, “with vaccination, my view is that it’s probably safe on balance. I need to go, ‘Well, it probably will protect my child’…they probably won’t have an adverse reaction. It is likely to be beneficial to them and beneficial to the community so I will choose to do it.” It is noteworthy that Pippa, who accepted the concept of community (herd) immunity that several other participants rejected, factored risk to others within this framework. Consequently, she saw vaccination as mutually beneficial, in that it mitigated both individual and communal risks.
While some parents focused on the vaccine risk compared to the risk of disease, others, like Daisy (SA), also weighed a perceived low risk from diseases in her geographic locality, reducing the perceived benefit of vaccination. “I am not saying it’s a bad thing to be vaccinated against diseases ... I do believe that they have stopped diseases in the past. But I also think there’s not a huge amount of risk for the diseases that they are vaccinating against in this particular area”. Holly (SA) expressed similar views, with disease seriousness also weighing into her decision. “I just have a really strong belief and I believe, I guess, that I probably wouldn’t be swayed by an outbreak... Maybe if I was in Africa and it was Ebola and knocking people off left, right and centre, yep, I probably would be”.

Responsibility

With every significant decision for a responsibilised parent, there may be unavoidable consequences. Parents in our study had to navigate through the frame of responsibility for their decision, particularly if anything was to go wrong either way. Luhmann argues that when people distrust the social systems on which they rely and attribute responsibility, they have to then take on personal responsibility and develop levels of self-trust – responsibility for either positive or negative outcomes of distrusting fall squarely on the shoulders of the individual (Luhmann 2000, Luhmann 1979). Meg (WA) articulated this strongly; “If something had have gone wrong after making that decision [not to vaccinate], I wouldn’t be able to live with myself. So if they’d caught a disease, or become blind or died, I wouldn’t have been able to live with myself. Life just wouldn’t be worth living because my baby died, because it would be your fault and there is no other way to put it: it’s your fault”. Such anticipatory regret has been found in other qualitative studies on parental perceptions of childhood vaccinations (Leask et al. 2006). Meg (WA) went on to talk about needing to ‘shoulder the blame’ and situations in which ‘blame’ would instead fall on others, such as the government or pharmaceutical industry. “I suppose if you immunised and something goes wrong, you point a finger at the government ...or the pharmaceutical company, or the vaccination. But when you’ve made the decision not to vaccinate, that finger is pointed squarely you, and I couldn’t live with that”. Fear of personal
responsibility and blame in the event of an adverse event led Meg to vaccinate her child on a delayed schedule.

Those parents who made a decision not to vaccinate believed that they needed to take on further responsibility for the health and wellbeing of their child. Here, salutogenic parenting came to the fore, with parents aiming to improve and sustain natural immunity through labour intensive practices. They viewed this as key to healthy childhood development and an integral strategy to counter-balance non-vaccination; a perceived risk mitigation strategy recognised earlier by Rogers and Pilgrim (1995b). For example, Holly (SA) talked about balancing the risks and responsibilities associated with her daughter contracting an infection, and her implementation of health-promoting activities. “I was home with [daughter’s name] for a while so I felt that was a protective factor, and healthy food was important. Back then I was the one for the organic food. I did keep a close eye on her but I was...I mean I wasn’t continuously nervous, but I was continuously almost aware that we haven’t vaccinated her and that there are risks involved in that too”.

Rejection of all vaccines did not mean that parents assumed there was no risk. Consequently, responsibility for the vaccine refusal meant being ready to take preventative action, as Natalie (SA) explained with regard to a potential measles outbreak. “If you hear of an outbreak you keep your kids away. You take normal precautions and you keep their immune system up, you know, extra doses of vitamin C and keep them healthy.” The risk management strategies employed by Natalie and many parents included quarantine and measures they perceived as strengthening the child’s immune system, in case they were unknowingly exposed to diseases. However, it was not always easy to ‘get square’ with this responsibility. Cally (SA) (like Meg earlier) talked about personal responsibility related to her worries of her daughter contracting an infectious disease from others. She saw her position as heightened by what she said were judgemental and fearful comments from her mother: “Her words were ‘It would be terrible if something happened to her’. And that’s really hard you know.” This is another example of anticipatory regret, though notably it did not sway Cally to vaccinate, possibly because it was imposed externally. Alice (SA) believed the likelihood of her unvaccinated child becoming ill was small, but if she had seen more of a risk she said she would find it difficult to handle the responsibility. “I kinda weighed up my options and weighed up the chances of that
[contracting a communicable disease] happening that it is so minimal that in a healthy body it is not likely to happen. Whereas if it was kinda like a really bad thing I would not be able to handle that responsibility”.

Parents were well aware that family, health care professionals and sometimes partners did not align with their decision. This further reinforced their understanding that it was their responsibility to validate their decisions on an ongoing basis. As Reich (2014) noted in her study of American vaccine refusing parents, this responsibility often played out in highly gendered ways, with mothers ‘naturally’ assuming the role of decision-making authority. For Alice (SA), the lack of input from her partner heightened her responsibility in refusing vaccines. This drove her to research the science behind her decisions, knowing that if anything went wrong she would feel responsible, “Yeah, it’s like with schooling, I made all the decisions based on, you know, research that I have done ... I felt that it was my responsibility...He really just didn’t have an opinion...so that put more pressure on me. So I furthered my research, and if there was any negative outcome I would feel 100% responsible. So that actually made me more scientific about it”.

Given that a number of parents believed that the risks of vaccinating were higher than the risks of not vaccinating, consequently they framed their considerations in terms of the benefits of not vaccinating. (They employed an assets-based rationale rather than one framed negatively in terms of risk.) Such a rationale was advanced by Evan (SA), who perceived that refusing vaccination for his daughter made him a better father, since he needed to consider her health in more depth. Like most of the parents in our study, he mobilised salutogenic parenting as part of this. “I became a better parent because I knew I have to actually keep my daughter healthy. I can’t just go, ‘Ooh, she is having her shots now, my work is done, she’s not my responsibility,’ you know. My responsibility goes on now, so I make sure she doesn’t have genetically engineered food...I am a better father in the sense, like, that I am more nurturing. I have had to put the work in....I decided that the state wasn’t going to be responsible for my child’s health. I was going to be responsible ...[S]he has had whooping cough. And I took her out of school and took time off work and made sure I was with her that whole time she had it, to make sure she was going to be okay. She’s had the measles and I spent, you know... [A]nytime she has been sick, I just made sure that I took time off work and I spent the time she needed to actually recover from these things.”
Some parents also had a perceived social responsibility, borne from consideration of the impact of their decisions upon the health of the broader community. Clara (WA), for example, talked about her feelings of social responsibility and her concern that her daughter may pass on a communicable disease, especially young babies, “I don’t let her around small kids, even if she got a runny nose... that’s probably where I differ from other people, a lot of other people, in my non-immunising community. The whole idea that if you’re healthy, you know, your baby’s even healthier and are not going to attract these diseases...is misguided because it does happen. I’m more concerned about her giving something to somebody else. You know, once she is in a school environment she can infect other people or newborn without me being there. I would never forgive myself if she was to be a carrier of pertussis or something like that”. Vanessa (SA) talked about how she excluded her children from school if they are unwell, as a way of attempting to reduce the risk to other children. “My kids are excluded when unwell...other parents are just jamming Panadol into the kids mouths and sending them back in.”

Responses and Reflexivity

Despite the efforts to which the parents went in order to protect and promote the health of their children and the community, almost all experienced judgement by others, including friends and family, vaccinating parents and some healthcare professionals. These responses of others (particularly those made during the decision-making process) and how parents digest them form part of the risk reasoning process. Accordingly, we widen the scope of parental risk engagement to consider risks to social relationships and medical care, considering that parents must also deal with the potential risk of unwelcome responses and problematic encounters.

Within the social realm, Dianne (SA) described several situations when people became angry with her, which led her to ‘withdraw the information’ on her vaccination decisions and only ‘tell the people who need to know’. Denae (WA) had received advice from her sister regarding what to say to those individuals who questioned or judged her decision not to vaccinate her children. “Because that’s what I am scared of, I guess. Other people. I don’t want to have that conversation and get kind of looked down upon because I am
stupid or try to make a decision like this, that I think is best for my kids.”. Denae continued to talk about feeling judged on online parenting discussion sites, which led to her to cease communicating that way. “I shut down... because a lot of the women on there think that if you are not immunising, they give you a lot of shit and they’re really rude about it. I have never posted anything because I’m scared about then being called stupid and all the other things”. Charlotte (SA) described judgement from her parents about her decision not to vaccinate her children, but her comfort with her decisions demonstrated self-trust and responsibility. “It doesn’t really matter, does it, what they think, because they’re not their children.... They’re our children. Sure, they don’t agree with everything that we’ve done, and if it was them, obviously, they would have vaccinated. But, essentially, it’s like, ‘Well, they’re our children and our responsibility, and we’re their guardians, and we make the decisions, not anyone else”.

On a broader scale, Steve (SA) talked about his perceptions of double-standards in society, whereby free choice does not appear to extend to making a decision not to vaccinate your own children, due to stigma and judgement. He reflected that in his profession (naturopathy), there would always be two sides to consider regarding treatment options, and freedom of choice would matter. “If I was wanting something for a patient of mine that I felt was good for them, I would want to let them know ‘hey, are you really sure that by rejecting this’ – but at the end of the day I have to respect – if anybody that comes to me doesn’t want what I offer them, that’s their call.” He was frustrated, however, that this was not reciprocated in mainstream medicine: “yeah, it wasn’t respected, my choice”.

Parents’ interactions with some health professionals brought to the fore responses of which they were both fearful and disdainful. Steve (SA) stated, “Vaccination is in its own category. ... it’s still a sacred cow that can’t be touched”. He argued that healthcare professionals do not, in his experience, listen to or consider the possible benefits of not vaccinating children. Angela (WA) talked about her experiences of judgemental GPs, which then impacted her likelihood to seek treatment for her children, “I put off going to the doctor whenever the kids are sick because I know the few times I’ve been in, it’s been quite a negative reaction. So unless the kids are really sick, I don’t tend to take them to the doctor. Which I, like – I need to find a doctor that is open to people who don’t immunise”. Cally (SA) talked about a friend’s experiences of feeling
judged when taking her unvaccinated child to hospital. Cally said this impacted her trust in hospitals, generating fear of taking her own child. “She said that when she took him into hospital with chicken pox... the looks she got from the nurses, she was basically judged and not helped as much as she could have been, and just ostracized... That’s really scary as a parent. Going into a hospital and say, ‘Oh well, she is having a complication with chicken pox’ and ‘No, she is not vaccinated’. You know, I would try and keep her at home and treat her naturally. ... I would be fearful of going to hospital. So that sets up maybe not giving her the best emergency care”.

Many parents expressed frustration at sometimes condescending and disempowering interactions with healthcare providers. Patronisation and disrespect led to distrust in the case of Pippa (SA). “I just got hit with sometimes just absolutely ridiculous statements. My GP, for example, she just told me something that if she had any scientific knowledge she never would have made the statement she made .... and she was so rude and dismissive... So I was just, like – each interaction like that erodes my trust further”. This led her to seek a GP who enabled her to feel respected and listened to, despite their differences of opinion regarding parenting/ health practices. This increased her willingness to engage in information sharing with this GP. “I know she’s not a fan of home birthing. She thinks breastfeeding two year olds is a bit weird...but she’s like ‘well, you go ahead and do that.’ And I’ll talk about the World Health Organisation’s recommendations around lactation, and I’ll talk about my reasoning for doing that, and ‘Can you please show me the paper that demonstrates there’s harm from doing it, then, because there is no such paper.’ So I have felt treated with respect. I have been treated as an informed, sensible adult who can have a discussion about the risks and benefits with another professional, and that has been a big difference for me, and that has enabled me to feel more trust, in that we can both admit vaccines are not perfect, that sometimes adverse reactions happen”.

**Concluding Comments**

Parents’ perception of risk is critical to their decision-making regarding vaccination (Kaufman 2010, Berezin and Eads 2016, Betsch et al. 2010). It is critical to understand how parents who wholly or partially reject vaccination interpret and make sense of risk if we are to identify appropriate interventions to
maximise uptake (Samad et al. 2006, Feinberg and Willer 2015). Parents in this study adopted a level of social and personal responsibility (self-trust) to mitigate negative results that might ensue as a consequence of this decision. They assumed responsibility through salutogenic parenting, which incorporated prevention strategies aiming to maintain child health and reduce the risk of infection and illness. Parents’ risk management strategies were often constructed very broadly, including restricting children’s exposure to the perceived negative effects of commercialism and technology, an example of a political economy and/or anti-capitalist ethos which may understandably construct power/hierarchy/private-sector as risky. Given the choice to deviate from the government recommended childhood vaccination schedule, parents accepted and actively took on (and sometimes grappled with) the responsibility for their personal choice. Some parents extended responsibility for the safety of others (for example, spread of disease to babies who are not yet vaccinated), which led to health behaviours such as quarantining their own children when they were unwell. (However, this may not be an effective strategy for preventing disease transmission due to incubation periods when children may not feel unwell.) A lack of clear guidance to navigate the extensive immunisation literature (and the research surrounding vaccine safety) contributed to anxiety in some parents who still felt uncertain regarding the evidence on which they based their decisions. Alongside the responsibility associated with not vaccinating their children came blame and judgement. Vaccine refusing parents felt judged by family, friends and some healthcare professionals. The innate sense of responsibility that accompanies parenthood, turbo-charged by responsibilisation and professionalised parenting, brings with it a felt or real external judgement from opposing groups (Brown et al. 2012). Parents’ non-vaccination stance had negative implications, not only for their social relationships, but also for their access to healthcare services, due to poor experiences in some health care encounters. Conversely, they valued a respectful relationship with health professionals when they found it, and indeed commented on the respectful way that interviews were undertaken for our research.

Perhaps the most compelling (but unsurprising) finding was that the parents interviewed just wanted the best for their children, and sought to take on (via responsibilisation) the maintainance of health and wellbeing. In general, all parents want to do their best for their children. However, our participants actively wanted to take agency and responsibility back from the State and replace what they regarded as the negative consequences
of vaccinating their children with positive consequences of salutogenic parenting. This reading of our data reframes the act of not vaccinating from being deficit-based (i.e. parents are doing something wrong) to being assets-based (parents have a particular logic and are basing their lives around what they regard as positive parenting and health promotion for their children), fulfilling the notion of parents as ‘subjects of freedom’ (Kaufman 2010). Following Feinberg and Willer (2015), we are not simply trying to ‘change’ what we see as the ‘wrong’ decision – we seek to understand the logic and moral position of parents so that communication can occur in a socially, culturally and ethically appropriate way, helping parents make decisions that are both evidence informed and consonant with their values. Health systems and professionals will communicate to parents who don’t vaccinate. If this is to be effective, it must recognise these values.

Whilst our paper has major strengths in terms of theoretical and empirical depth, we note some potential limitations that need to be borne in mind when attempting to infer from our findings. Firstly, we have analysed data from two different studies, undertaken by two different researchers in different Australian cities. Whilst the different studies aimed at understanding parental decision-making and rationalities, there may be some contextual differences which make our merging of data less than optimal. However, both of the researchers are authors on this paper (KA and PR), were involved in the analysis of the merged dataset and attest to the comparability of data. Secondly, whilst the parents in both studies had either partially or fully rejected vaccinations for their children, they do not necessarily represent the views of all parents who reject (partially or fully) vaccinations, although this is the case for all qualitative research whereby the epistemological basis is about generating understanding rather than explaining patterns. We hope that our findings can be explored in other countries and settings in order to understand how the knowledges, perspectives and practices may be similar or different.

In summary, parents engage in practices and behaviours that they perceive optimise their children’s health and negate the need for vaccination. As a result of employing this logic, they subsequently emphasise their personal responsibility for decisions and consequences. This personal responsibility starts in the realm of research to inform decisions. Parents in this study all reported undertaking research in order to make decisions and to defend and personally justify them. They spoke at length about their perceptions and fear of
the risks from vaccinating their children relative to the benefits of not vaccinating them. Their lack of trust in governments, medical science and the pharmaceutical industry (Attwell et al. 2017) often led them to construct vaccines as both unnecessarily risky and of little/no health benefit for their child. The parents’ salutogenic logic and diligent research was consistent with the maxim that with taking risk comes the assumption of responsibility. This responsibility was not necessarily easily navigated, however. Information gathering on the risks and benefits of vaccinating/not vaccinating often created uncertainty, confusion and anxiety. Parents recognised the existence of conflicting information, but also the social and individual responsibility which came with their decision. Nevertheless, once parents had made the decision not to vaccinate, they were comfortable with the responsibility, maintaining and promoting their child’s health and wellbeing but also expressing a sense of social responsibility for the health of others. Finally, although they took personal and social responsibility for their decision not to vaccinate, they bore both blame and stigma from friends/family and healthcare professionals which they believed to be unfair and unfounded. Health care professionals need to remain open to discussion regarding vaccinations with vaccine hesitant and non-vaccinating parents. An ‘open door’ policy enables individuals seeking vaccine information and advice to access services, assured they will be received in a respectful manner, so that conversations and the building and maintenance of trust can occur.
References


