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Parenting and the vaccine refusal process: A new explanation of the relationship between lifestyle and vaccination trajectories

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ABSTRACT

Recent research illuminates the characteristics of non-vaccinating parents in well-defined geographic communities, however the process by which they came to reject vaccines is less clearly understood. Between September 11th, 2017 and February 20th, 2019, we recruited a nationally derived sample of Australian parents of children under 18 years who rejected some or all vaccines for semi-structured interviews. We used various strategies, including advertising on national radio, in community centres and playgrounds in low coverage areas, and snowballing. Grounded Theory methodology guided data collection and analysis.

Twenty-one parents from regional and urban locations were interviewed. All spoke of wanting happy, healthy, robust children. All endorsed parenting values and approaches aligned with modern societal expectations of taking responsibility for their child's health. They varied, however, in their lifestyle and vaccination trajectories. Participants self-identified as situated along an 'alternative' to 'mainstream' lifestyle spectrum and had moved both away from and toward vaccination over time. Some had decided before birth that they never would vaccinate their children and had not changed. Others stopped vaccinating after perceived post-vaccine reactions in their children. Still others initially rejected vaccines, but eventually accepted them.

The variation and dynamic nature of the vaccination trajectories described in this study suggests that vaccine refusal is not a static trait but rather the result of ever-changing experience and continual risk assessment; not all non-vaccinating parents fit the 'alternative lifestyle' stereotype. This suggests that nuanced personalised engagement with non-vaccinating parents is more appropriate than a one-size-fits-all approach.

1. Introduction

Child mortality due to vaccine-preventable diseases has diminished since the mid- 20th Century (Stanley FJ, 2001). Publicly-funded programs and community support for vaccination means children across the industrialised world, including Australia, enjoy a low incidence of once-common illnesses. Vaccination constitutes both an individual good through protecting the child and a public good through limiting disease transmission. Most Australian parents accept vaccines, with 94.74% of all five year-olds fully immunised (Australian Government Department of Health, 2020). Despite vaccination's success, some parents refuse vaccines for their children, and such parents are often judged harshly, both as parents and community members (Rozbroj et al., 2019). This harsh judgement and the accompanying outrage were heightened with recent outbreaks of measles and whooping cough, which media sources often blame on non-vaccinating parents (Bye, 2017; Daniel and Olsen, 2019).

Vaccination is only one aspect of parenting, and contemporary parents are subject to strong societal expectations. As Faircloth points out, 'the word "parent" has shifted from a noun denoting a relationship with a child (something you are), to a verb (something you do)' (Faircloth, 2009 p15). In her classic work on the dominant ideology of intensive parenting, Hays describes a 'model which advises mothers to expend a tremendous amount of time, energy, and money in raising their

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children' (Hays, 1996 pX). Mothers are expected to become experts in all aspects of childhood, including nutrition, cognitive development, and psychology, with 'experts' telling mothers 'to be constantly attentive to the child's needs, to be alert to each new developmental stage, and to learn how to read the child's cries and organize the child's play activities', judging them harshly should they fail (Hays, 1996 p71). Building on Hays' insights, Kukla argues that mothers are judged on whether they live up to cultural norms while negotiating 'increasing medicalisation of children's behavior and bodies' (Kukla, 2008 p69).

Intensive parenting scholarship has more recently extended to fathers, finding that they too are subject to the demands of intensive parenting culture, albeit in different ways (Shirani et al., 2012). It is in this context that Australian parents make expert-recommended and socially expected medical decisions such as whether to immunise their children, which may help explain the harshness by which society judges vaccine-refusing parents (Rozbroj et al., 2019).

Vaccine refusal is highly controversial in Australia. Some mainstream media outlets report disparagingly on parents who do not vaccinate (Harvey, 2015a), and have been important advocates in the introduction of punitive policy levers (Harvey, 2015b). In January 2016, the Australian Federal Government tightened legislation linking children's vaccination status to family support payments, with families of children not fully vaccinated no longer able to claim 'conscientious objector exemption' and thus denied family tax benefits and access to childcare subsidies (up to AUD$26,000 per year) (Department of Human Services, 2019; Omer et al., 2019). Furthermore, four Australian states (New South Wales, Victoria, Western Australia and South Australia) have restricted children who are not fully immunised from attending childcare and pre-school.

Several recent studies explore non-vaccinating parents' views, often focusing on tightly defined localities: closed communities such as Sobo's study of a Waldorf (Steiner) school community in California (Sobo, 2015); or geographic locations where non-vaccinating families are known to cluster (Attwell et al., 2018; Helps et al., 2019; Ward et al., 2017). These studies show non-vaccinating parents perceive a deterioration in health in Western societies (Helps et al., 2019) and are critical of Western medical epistemology (Ward PR, Attwell K, Meyer SB, Rokkas P, & J, 2017), questioning the evidence justifying vaccination (Ward et al., 2017), and embarking on a quest for the 'real truth' (Helps et al., 2019). Parents' interactions with mainstream health systems are often marred with negative experiences that introduce doubt. Participants in these studies report mistrust in the expert systems underpinning vaccination policy and practice (Attwell et al., 2017), and describe taking a 'natural preventive' approach to health which includes a focus on things like organic food and reduction of 'bad chemicals', supplemented with complementary and alternative medicine (Attwell and Smith, 2017; Ward PR et al., 2017). This 'salutogenic parenting' is entwined with a broader social identity, with the parents themselves in some cases acknowledging that their position had both personal and cultural elements (Attwell and Smith, 2017; Helps et al., 2019). It has been reported that Australia's introduction of more stringent vaccination requirements strengthened the resolve of some of these parents not to vaccinate (Helps et al., 2018).

While these studies enrich our understanding of vaccine refusal in well-defined geographic populations, key questions remain about the transferability of this knowledge to other communities, and the *processes* by which parents arrive at vaccine refusal or delay. We address this by analysing data from a nationally derived sample of parents, exploring the diversity of parental experiences and understandings. We derive an empirically-grounded mid-range theory of the process by which parents arrive at (or depart from) a position of non-vaccination.

2. Methods

We sought to elicit and explain patterns and variation in the social process of parental refusal of childhood vaccines, as expressed by the parents themselves, using a grounded theory study design (Charmaz, 2014).

2.1. Interview structure

Semi-structured telephone, online and face to face interviews were conducted using an interview schedule iteratively adjusted as data analysis progressed (Charmaz, 2014). The interview centred around three key lines of inquiry: 'Tell me what's important to you as a parent', 'Tell me how you got here' (with respect to vaccine refusal), and 'Tell me about the people, experiences, or other things that were influential in helping you come to your current position on vaccination'.

2.2. Sampling approach

Australian non-vaccinating families are generally located in geographical clusters (Beard et al., 2016), and previous studies used purposive sampling strategies which leveraged this. In contrast, to reach parents across Australia, we took a three-tier national-local-personal approach to recruitment: nationally, we advertised using a national radio station (and their associated Facebook brand) whose focus demographic is 'kids and their adults'. We approached a number of national Facebook parenting groups, particularly those for 'natural parents'. Similarly, we approached more localised Facebook pages for parents in geographical areas known to have below-average vaccine uptake and advertised at local libraries, on community noticeboards and in playgrounds in these postcodes. We advertised through groups and institutions commonly associated with vaccine rejection, such as local Steiner schools, and national homeschooling conventions. Finally, we sought to utilize participants' personal networks through referral sampling (Atkinson and Flint, 2001).

Once contacted by an interested parent, we checked the age and vaccination status of their children (eligible parents had a child under 18 years who had ever refused some or all vaccines for their child[ren]). Consenting parents were sent a participant information sheet and asked to nominate their preferred interview mode (telephone, online or face to face), and choose a pseudonym to ensure de-identified data collection and analysis. Interviews were audio-recorded and transcribed using a confidential transcribing service.

We intended to employ theoretical sampling in line with Grounded Theory principles, however non-vaccinating parents are a small population estimated to be 2–3% of all parents (Beard et al., 2016) and issues of trust make recruitment challenging. Hence, we interviewed every parent recruited to obtain sufficient data for our analysis, resulting in a purposive rather than theoretical sample for reasons of logistics rather than design.

2.3. Coding development and data analysis

The research team comprised two groups: those who had recently conducted research with non-vaccinating parents (KA, CH and PW); and those who had not recently undertaken such research (KW, JL, SC). In order to incorporate both 'experienced' and 'fresh' perspectives, all six researchers independently openly coded the first three interviews, and then discussed and agreed on initial emergent codes. A second coding triangulation exercise was conducted after seven more interviews, ensuring methodological rigor. For subsequent interviews, the coding progressed through focused coding to identify the processes occurring for parents and the emergent codes were discussed in periodic research group meetings. As the categories developed, connections between them could be drawn through a combination of inductive, deductive and abductive analysis. The result was an emergent explanatory mid-range theory explicating lifestyle and vaccine decision-making trajectories. Data collection continued until theoretical saturation was reached (Saunders et al., 2018).

To promote a reflexive analytical approach, the primary researcher

(KW) kept a detailed memo throughout the entire research process, enabling continuous critical reflection of how her own positions on the subject related to the research (Begoray and Banister, 2010).

2.4. Ethical approval

This study was approved by the University of Sydney Human Research Ethics Committee, approval number 2017/500.

3. Results

Between September 11th, 2017 and February 20th, 2019, twenty-one interviews were conducted with parents from five of Australia's eight states and territories, with participants from a variety of regional, urban and city locations (Fig. 1). Most interviewees were mothers: one father, and one parent who didn't want their gender recorded took part in the study. Parents' ages ranged from mid- 30s to mid-50s, and they had between one and six children, ranging from 9 months to 33 years old. All had at least one child 18 years old or younger at the time of interview, making them subject to the Federal policy withholding benefits from unvaccinated children. Interviews lasted an average of 1 h 9 min, ranging between 37 min and 2 h 7 min.

A common drive to fulfil the role of the responsible parent underpinned the pathways to non-vaccination described by the parents. We identified two distinct but related trajectories in the parent's narratives: their pathway over time to their current lifestyle approach, or *lifestyle trajectory*, and their pathway over time to their current position on vaccination, or *vaccination trajectory*. We identified three general *lifestyle trajectories* described by the parents in this study: 1) always 'alternative'; 2) starting out 'mainstream' and shifting toward 'alternative' over time; and 3) always 'mainstream'. Intertwined with these lifestyle trajectories were three *vaccination trajectories*: 1) no change in position (never have vaccinated); 2) a single change in position (starting out vaccinating and then stopping, or starting out not vaccinating then starting) and 3) two changes in position (starting out vaccinating, then stopping, then starting again). We expand on these below.

3.1. Fulfilling the role of responsible parent

The processes of vaccine rejection described by these parents displayed both commonality and variation. We will focus first on the commonality.

All 21 parents referenced the values and priorities that underpin modern societal expectations of 'the good parent'. They universally spoke of wanting happy, healthy children who are physically and emotionally robust, and all approached parenting in ways aligned to the intensive parenting model, expressing sentiments like Claire:

> 'I guess ultimately I really want our children to be as resilient and robust as they can be … I guess I'm very keen to do whatever I can to make sure that my children are as robust as they can be.'
>
> – Claire

A number spoke of the importance of respect for and connection with their children, often seeing their children as partners in their upbringing, and using words like 'thoughtful' and 'conscious' to describe their parenting approach. Many, like Amy, were careful to point out that they also set boundaries with appropriate discipline and sought to imbue values and sound moral judgement in their children.

> '[W]e're definitely not laissez-faire parents. We do set boundaries and hold those. But we also are fairly strong believers in meeting a child where they're at in terms of their emotional development.'
>
> – Amy

Participants were highly attuned to their children's health, wellbeing and developmental needs, taking active responsibility for meeting those needs. Many invested significant time and resources into providing the best environment for their children. For example, Jane had quit her

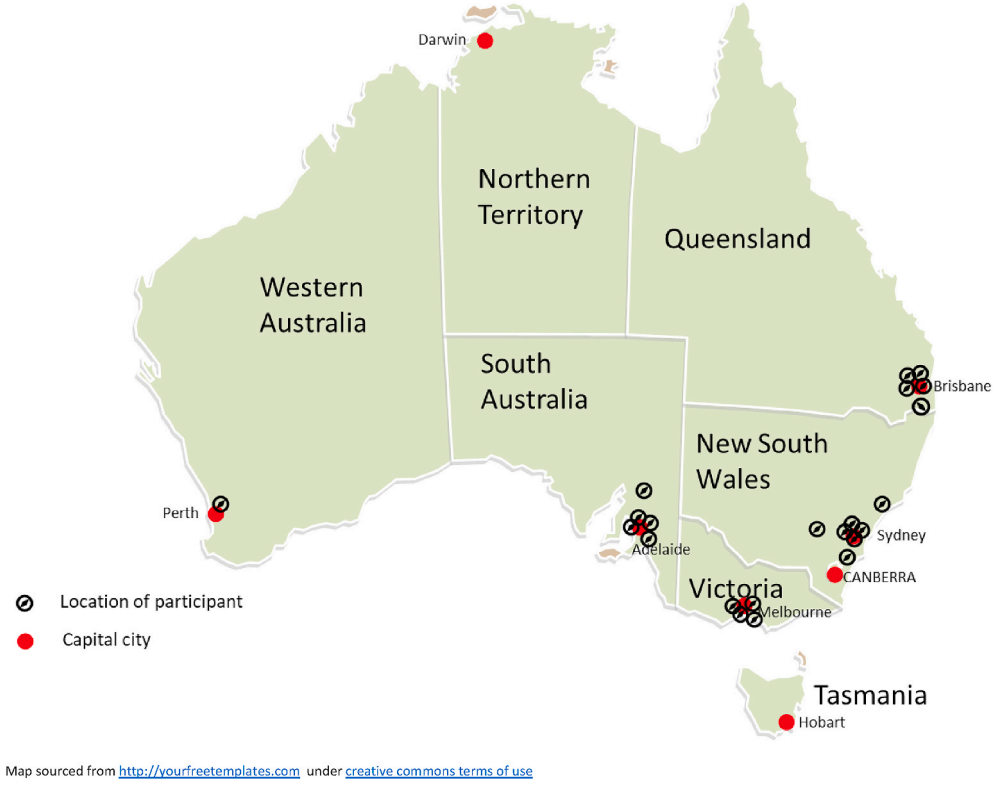

Fig. 1. Locations of study participants.

successful business and moved out of the city to provide a 'slower paced' life, with access to fresh air and home-grown vegetables.

> '[N]othing's more important. I have sacrificed so much for the child … My whole life has been coming up to this moment, I wanted to be a mother forever, and every decision that I make is with his best interests in mind.'
>
> – Jane

3.2. Enacting 'responsible parenthood' – three lifestyle trajectories

In public discourse, non-vaccinating parents are often described as leading an 'alternative' lifestyle (the unspoken comparison being with the 'mainstream' population) (Elliott, 2019). 'Alternative lifestyle' in this sense is used to describe people who are performing a specific type of social identity. Often critical of Western medical epistemology, they pursue 'natural preventive' approaches to health (Attwell and Smith, 2017; Helps et al., 2019). It became apparent that while some participants aligned themselves with 'alternative lifestyle' practices, others did not, or only did to an extent, indicating a spectrum of lifestyles. To better characterise this, we located participants' lifestyles on a spectrum from 'alternative' to 'mainstream'. We compared their self-described parenting and lifestyle practices with those described in other studies which explicitly sought participants who identified as living an 'alternative lifestyle' (Attwell, 2019; Ward et al., 2017).

Jane, for example, actively worked to avoid toxins in 'food, cosmetics, everything', aimed for 'clean air, clean water' and grew her own organic produce. We oriented her as alternative.

Amy described raising her family as vegan and pursuing natural health approaches to some extent, but still using Western medicine when required. She was therefore oriented on the boundary between alternative and mainstream.

Jay spoke of pursuing a varied diet and using Western medicine while mistrusting complementary and alternative approaches. Jay *didn't* mention things like preferring organic produce or pursuing a toxin-free environment and was therefore oriented as mainstream.

Parents explained these approaches to health and lifestyle in the language of responsible parenting already discussed. The diet and health practices described varied widely between individuals, and often changed over time.

Vaccine refusal was *not* consistently linked with taking up alternative parenting practices: instead, non-vaccinating participants in this study sat, and sometimes shifted, along the mainstream through to alternative parenting spectrum.

Several participants self-described as 'normal' or 'mainstream' when asked about their parenting practices. While they described a focus on healthy diet, for example, they still allowed sugar and processed foods, and tried to minimise screen time without banning it altogether. These 'mainstream' parents did not mention trying to avoid toxins or disconnecting from mainstream society. In contrast, other participants were closer to the 'alternative' end of the lifestyle spectrum, although only some of these parents self-identified as 'crunchy' (a colloquial Australian term used to describe parenting strongly aligned with visibly alternative lifestyle practices (Koelma, 2016)). Consistent with studies that have focused on these alternative lifestyles (Attwell et al., 2018), this group went to lengths to minimise exposure to toxins, such as removing all chemicals from the home, growing their own produce, avoiding western medicine in favour of complementary and alternative medicine, or distancing themselves from a 'mainstream' identity.

So while we observed an intensive parenting approach across all participants, they manifested this in varied ways. Parents' relationship to mainstream and alternative practices were also dynamic, changing over time. Here we observed three distinct *lifestyle trajectories*, examples of which are described in Fig. 2. The first group reported having always been inclined to follow a lifestyle towards the alternative end of the spectrum. The second trajectory involved starting at mainstream and moving towards an alternative lifestyle (usually in reaction to an adverse health experience). The third group described consistently following a mainstream lifestyle and did not describe using preventive health practices described by those following an alternative lifestyle.

3.2.1. The consistently alternative lifestyle trajectory

Seven parents followed the first, consistently alternative trajectory. They described histories of natural health approaches (prior to becoming parents), in some cases having been raised this way themselves. Some were strongly alternative, others straddled the boundary of alternative and mainstream. Although these parents varied in the degree to which they pursued alternative health practices, their commonality was not reporting a change in their focus over the course of their life. Amy, for example, was vegan for decades before parenthood, used attachment parenting methods, and breast-fed her child until he was three. Her lifestyle choices were on the boundary between alternative and mainstream and she had maintained them consistently over time (Fig. 2).

> 'I guess, you know when people talk about crunchy parenting, we probably are to a slight extent, but we're not right in there, I guess. Yeah, we tend to be, yeah, dabbling at the edges, I guess, in that [our son's] vegetarian, and my husband and I are both vegans, and I guess in that, we were delayed vaccinators, so it's probably the ways in which we were a little bit "crunchy". But in other respects, probably not so much … '
>
> – Amy

3.2.2. The mainstream-to- alternative lifestyle trajectory

Nine parents followed the second trajectory: they had shifted from mainstream towards a more alternative approach. Most of these parents explained their lifestyle change as a response to specific health issues, in many cases suffered by their child, for which they felt western medicine could not provide answers. Critically, parents did not pursue lifestyle changes as a means to perform an identity. Rather, they faced a health issue suffered by either themselves or a loved one. Where those issues concerned their child—consistent with their personal values and societal expectations of taking responsibility for their child's health—they looked for a solution that would work. Their experience of failure of western medicine, and their search for answers, brought them to alternatives. Josephine (Fig. 2), was brought up with a mainstream lifestyle, but after suffering health issues in early adulthood that Western medicine could not fix, she began pursuing more alternative approaches to life and health. For Julie (below), it was her son's health issues, which she associated with vaccinations, that led to changes in lifestyle for the entire family:

> 'Yeah, I suppose it's kind of evolved … we never used to be – I think I ate lots of meat pies and sausage rolls when I was pregnant with him - I guess we were probably very, very normal before. Just very mainstream … And then when he finally had his four-year vaccinations, he had this huge reaction, and developed all kinds of issues that we tried to fix in many different ways, and eventually it kind of came down to changing his diet, and getting him onto a gluten free, dairy free, everything free diet, so yeah, that's kind of led us down there.'
>
> -Julie

3.2.3. The consistently mainstream lifestyle trajectory

The final five parents followed the third trajectory, describing themselves as always and still mainstream in their lifestyle and health choices. Sally (Fig. 2) described her lifestyle approach as "normal", and didn't describe a history of being any different:

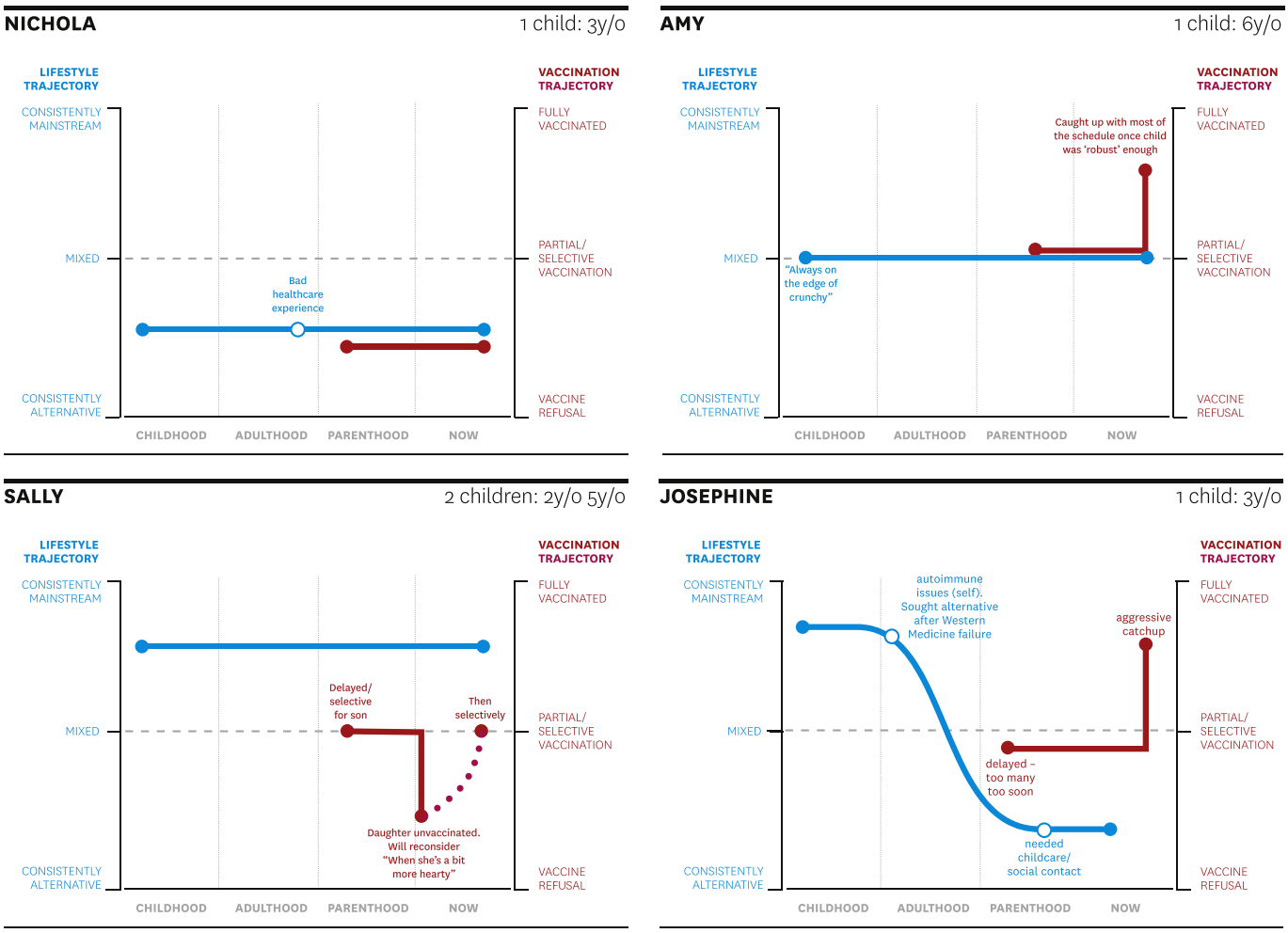

Fig. 2. Exemplars of lifestyle and vaccination trajectories as narrated by select participants.

'So we're not gluten free, we're not sugar free …. we just eat a really well balanced diet that has lots of vegetables in it and lots of fish and lots of meat … [U]nlike, I think, a lot of other parents that are concerned about vaccination, I'm not vegan … I don't consider myself an extreme parent in any regard.'

– Sally

3.3. How I got here: three vaccination trajectories

In describing how they came to their current vaccination position, parents gave narrative accounts of their vaccination journey over time. These narratives appeared to follow one of three *vaccination trajectories*, culminating in their current position (Fig. 2).

These *vaccination trajectories* linked to the lifestyle trajectories participants described in a way that was not necessarily causal, but certainly intertwined. There were those who started out rejecting vaccines and hadn't changed their position (the *Never Have Vaccinated* trajectory); those who transitioned from one position to another (the *Changed Position Once* trajectory), for example starting vaccinating and then stopping; and those who started out vaccinating then stopped, then returned to vaccinating again (the *Changed Position Twice* trajectory).

3.3.1. The never have vaccinated trajectory

Five parents in our sample narrated the first type of trajectory. Parents like Jane (below) and Nichola (Fig. 2) had made their decision to refuse vaccines and never changed their minds, and had always pursued an alternative lifestyle, or adopted and maintained one (Fig. 3).

'For me my mind was made up several years ago, before I had a child'

– Jane

3.3.2. The changed position once trajectory

Most parents in our sample narrated the second type of vaccination trajectory. They described starting in one position and moving to another, with twelve moving from vaccinating to not vaccinating, and one moving the other way. For some of these parents, changes in position were prompted by an initiating occurrence, such as a perceived adverse reaction to a vaccine suffered by their child, or themselves, or someone they knew. Jenny's three-month-old baby had a severe medical episode following her vaccinations which resulted in a hospitalisation:

""[I]t wasn't really something that I'd questioned. Even though I knew you could have a reaction … But after her reaction, that did put the fear in me because it was scary.'

– Jenny

Following this Jenny stopped vaccinating all her children.

Other parents who moved from vaccination to non-vaccination described a different trigger. Rather than identifying a specific event, they had a background of being unsure about vaccines, which led them to question the safety or necessity of it for their child, usually as a result of a perceived vulnerability due to health issues. Amy (Fig. 2) was very cautious with what she exposed her child to, including vaccinations.

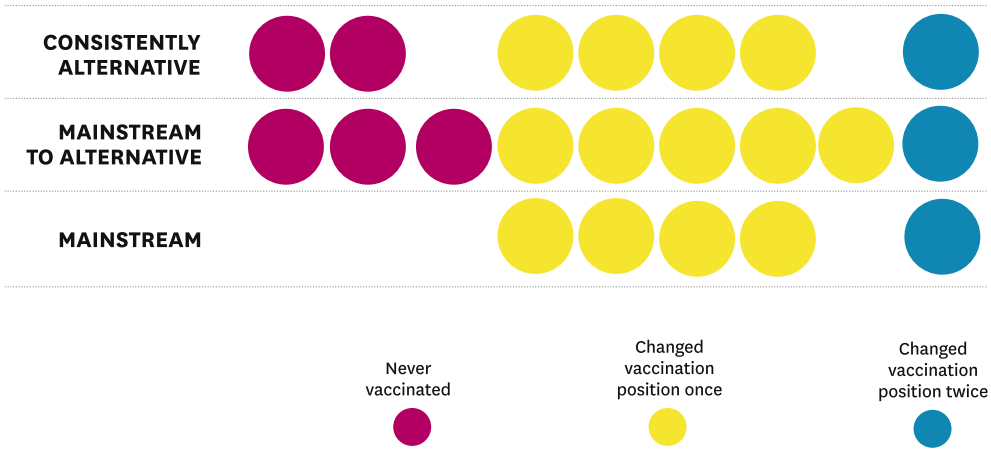

Fig. 3. Distribution of participant vaccination trajectories across lifestyle trajectories.

Following a period of intense self-directed investigation, and perceiving her child was growing more robust as he got older, she eventually selectively caught her child up with most of the recommended schedule:

> 'We hadn't really discussed it, when I was pregnant, what our position was going to be on it … I think we started to probably talk about it within that first couple of weeks … and we went, "Mmm, I don't know." We're not really going out anywhere … I guess I would never have considered myself anti-vaccine. I would consider myself pro-vaccine with some worries that I really had to iron out before I was prepared to 100% commit.'
>
> – Amy

For still others, it was a combination of starting in a place of questioning, and then being catalyzed into rejecting vaccines by a particular event. Catalyzing events varied and included emergent health issues suffered by the child, and negative experiences with the health care system that fostered mistrust. For example, some participants' experiences with pregnancy vaccines impacted their stance on childhood vaccines later:

> '[The] *first thing was I got vaccinated for whooping cough when I was pregnant and then … when I did my research I found out that actually the vaccine is a triple vaccine … They were just talking about whooping cough, my GP was like, 'Yeah it's whooping cough vaccine' and never did anybody tell me I was getting vaccinated for something else as well … So that really made me angry.'*
>
> – Matilda

3.3.3. *The changed positions twice trajectory*

Three parents narrated vaccination trajectories that fit the third type, where they started at one position (vaccinating), moved to another (stopped vaccinating), and then have since moved back to or toward their original position (vaccinating). As with the second type of trajectory, the first change in position was often associated with an initiating occurrence. However, personal experience and a re-assessment of risks made them reconsider their new position. For Julie, it was a combination of disease experience, self-directed investigation, weighing of perceived risks and intuition:

> *'I guess it probably came down to gut feeling at the end … I've had whooping cough. I thought, "Ah man, if I can save you going through that, and all you have to have is a needle, you know, maybe I'd do that." … so then I did a lot of searching, and I watched one great documentary … and I went "yeah, okay, life is risky, but let's choose which risk we're going to take", and that's when we decided okay, let's get her vaccinations.'."'*
>
> - Julie

3.3.4. *Turning away from vaccination: feeling pushed and the fear-denial-abandonment-quest narrative*

Following the initiating occurrence or place of questioning that they started from, these parents described common traits in their respective vaccination trajectories. One common experience was feeling pushed toward conforming to a pre-determined and inflexible vaccination program, despite their conviction that this was not right for their child. This left them feeling that their agency in their child's health care decisions had been undermined, which conflicted with their desire to assume responsibility for their child's health.

> *'[I]t doesn't feel good to be forced because of money to do something that maybe you do have some reservations about.'*
>
> - Anne

> *'You don't have any control … I just do feel like I am railroaded into a polarised view, rather than being talked to like an intelligent human being.'*
>
> – Elizabeth

There was also a commonality to parents' narrations of adverse occurrences that contributed to a decision to not vaccinate. Each narrative had four key elements:

1) fear in response to what they felt had happened to their child;
2) medical professionals' refusal to countenance their perception that their child had suffered an adverse reaction to a vaccine;
3) a consequent feeling of abandonment by the medical establishment; then
4) this sense of abandonment forcing them to embark on a quest for answers to the health issues that plagued their child.

Elosie and Julie both shared similar stories:

> *'It was terrifying. It was really scary and it was really hard to get any help with it too, medically. So we rang the doctors … and they didn't really believe that she was having a reaction. It was just a thing that coincidentally happened.'*
>
> – Eloise

> *'It was pretty scary at the time, but I think probably more than that, was then that there was medical denial. "Oh my goodness, no, this couldn't have happened from the vaccination", and then the lack of support afterwards kind of then made me go "Ooh, dear." You're really on your*

own then if something bad happens. … There was just no support, which, I suppose, then you have to start looking for alternative medical practitioners.'

– Julie

This experience (fear-denial-abandonment-quest) often triggered a period of diligent self-directed investigation. Most parents in this study spoke of 'doing their research', however their reasons varied depending on their vaccination trajectory. Some on the *Changed Positions Once* trajectory described searching for information during the four-stage quest. Others on the *Never Have Vaccinated* trajectory sought information to retrospectively justify their intuitively held position. Katie (*Never Have Vaccinated*) intuitively decided not to and then sought information to support her position:

'[S]o when I made that decision about my first child, that's when we started doing research and I looked into, I think, every single thing that I think there was possibly to look into, on the internet, whatever books, whatever studies.'

– Katie

For many, investigating immunisation was a kind of 'due diligence' undertaken during the vaccination decision-making process.

'I'll just make sure I've done my homework, and then if I make a decision one way or the other, then at least I know that I can wear it.'

– Amy

Reasons for investigating vaccines varied between parents, but most went to great lengths. Sally used medical databases to search for vaccine-related information, relating that she had "four lever-arch folders" of information that she'd collated, while Josephine investigated each of the individual ingredients listed in the vaccine packet insert, looking for toxicology studies on each to aid in her decision-making.

'I kind of really set myself a goal to find out on my own, and I never kind of went on any anti-vax websites or pro-vax websites. I tried to kind of come to the decision on my own based on my own evidence. [I] used PubMed and research tools that were, I suppose, accredited tools not just – not just I've gone on a website. I've read a number of books, I read some immunological studies and some big studies that … followed children or had looked at effects of specific types of vaccine over a number of years.'

– Sally

'So we looked at all of the options. Say, for example, the diphtheria, tetanus, pertussis vaccine there's two different brands on offer and they have quite different concentrations the toxoid and any adjuvants and things like that. And so I very methodically went through and researched what they were firstly, because a lot of them are given codes, and then found out what they were, and then went through and had a look at research papers about the safety of them, if they existed.'

– Josephine

Furthermore, these parents saw their extensive quest to find information about immunisation as what they 'should' do to make an informed decision in line with fulfilling their role as a responsible parent. They often expressed frustration that parents who go to such lengths are labelled as neglectful or less competent than their peers who follow the expected vaccination schedule. Eloise's research was driven by her sense of responsibility to both her family and her community, and she felt that in doing so she had done more than others:

'For me, it means that I have a responsibility to my children to make the best possible decisions I can about their healthcare and other stuff and I also have a responsibility to the community to balance my decisions about my children with the wellbeing of the community. And it's meant I've done a lot more reading, basically. I've done a lot of reading, I've taken an interest in it, I've done lots of reading.'

– Eloise

Lynda also felt that those who question vaccination are doing more than others in their information-seeking, and a sense of frustration at being derided as "ill-informed" in the largely pro-vaccination discourse.

'They are not asking questions. They just believe what they hear, and I guess, so many of the anti-vaccinators get frustrated with that too, because they go, "Well, hang on. We are the ones who have done the research."'

– Lynda

3.3.5. The place we're at now – parents' expectations at the time of interview

Participants had arrived at one of two current vaccination decisions: either maintaining their decision not to vaccinate, or catching up their child up to the recommended schedule.

Fifteen parents said they remained non-vaccinators and indicated that they would be unlikely to move from it. However, these parents gave one of two central and strongly contrasting justifications for this decision: either their child was self-evidently robust and didn't need vaccines, or their child was self-evidently vulnerable, and unable to cope with vaccines.

For parents who perceived their child as robust, the experience of seeing their thriving child not falling ill helped solidify their position that vaccines aren't necessary. Lynda believed her adherence to a highly health-focussed, toxin-free lifestyle had made her child robust enough not to need western medicine,

'She is about to turn five and she hasn't actually had any vaccinations at this point, but she has not been sick. She has not been to a GP. She saw a GP at four weeks of age, and she has not been to a GP in five years.'

– Lynda

In some cases, the parents felt their unvaccinated children were healthier than their vaccinated peers, like Emma, who said:

'[M]y girls who have not had vaccines, who have not been to day care and all that, they are really well-balanced people, they're very healthy. That's not to say they don't ever get sick, but they don't get sick as much as their peers, not even get close'

– Emma

In contrast, other parents perceived their child to be vulnerable or fragile, and remained focused on the potential risk vaccines posed. They believed it unlikely that they would ever change their position. Claire's child suffered health issues that she felt made him less robust, reporting that while she didn't necessarily see vaccines as a cause, she felt vaccinating him would contribute to ongoing health issues:

'Look I think he's been vaccinated up to six months but we haven't vaccinated him since then, in part because he's actually had a lot of gut issues himself and so I'm just concerned about his immune system.'

- Claire

Maralyn's child suffered developmental issues. She said that while she couldn't know for sure what happened, she believed there was a chance it was associated with vaccination and therefore could not bring herself to vaccinate any of her children afterwards:

'I still don't dismiss the risks of certain diseases, but I do feel that my family's genetic profile – I think my family should be medically exempt, but they [medical professionals] don't have the understanding yet to get to

that point where they have a medical exemption. So, I think the risks for my family are too great and I am comfortable with them not being vaccinated.'

– Maralyn

Three parents, despite their current stance, indicated that in some circumstances they *may* be willing to re-assess their decision. These parents appeared to be engaging in a continuous process that involved assessing and minimising the risks for their individual children. Considerations for risk assessment included future plans for travel overseas, a change to local disease threat, or if the child was perceived to have grown robust enough to withstand the vaccine. All three parents said that while vaccinating in future wasn't out of the question, it was unlikely.

'I was still willing to accept that maybe I would do and I probably still am now, still willing to possibly vaccinate. I think it's probably unlikely, but possibly vaccinate for the most threatening disease.'

– Jay

For a number of these parents who continued not to vaccinate, the removal of federal financial assistance coupled with some states' exclusion of unvaccinated children from childcare served only to solidify their stance and make them less likely to change their minds. Nichola contemplated moving to another country rather than be forced to vaccinate her child:

'[M]y husband and I said we will do whatever it takes – Our son is our number one priority. We're not going to jack him up in order to ensure he goes to school. We have even thought about, can we move to New Zealand, you know. We will move elsewhere.'

– Nichola

In contrast, other parents had been non-vaccinators, and were now catching up, some as a result of the financial pressure associated with the legislative changes. For policy-architects, this may appear to be a straightforward success. The parents, however, experienced it as being pushed: simultaneously expected to actively assume agency for their child's wellbeing, and having that agency undermined. For Eloise and Josephine, obtaining the vaccinations was an immediate, visceral reinforcement of their loss of parental agency.

'So he's had three out of four [vaccinations] *that he needs to have and there's been no reaction, so that's been a great relief … Practically speaking, government policy, childcare benefits. He'd really like to be able to go to after-school care because his mates go and so I discussed it with him and we talked about it, talked through the pros and cons and talked about the advantages of vaccination and why it's a good thing … he was scared to do it and decided to do it and it was hard work for us all, but he did it, he's doing it.'*

– Eloise

'I just want to get my degree finished in the timeframe that I've been given. So I can't keep doing night classes, I'm just going to have to bite the bullet and put her into childcare a couple of days a week. So we're on a bit of an aggressive catch up schedule at the moment which isn't ideal … it's been knocking her around a bit.'

– Josephine

In contrast, other parents who changed their position retained their agency in the process. Their changes were due to very careful and prolonged consideration of the risks posed by diseases, weighed against the vulnerability they perceived in their child and the resultant perceived risk of the vaccine, often after exhaustive investigation and deliberation. Despite retaining her sense of agency, Amy still found the act of vaccinating her child very stressful:

'I was often afraid if something goes wrong from this, I'll feel terrible. But conversely, if my child gets ill from something that was vaccine-preventable, I'll feel terrible! So it felt like a real Catch 22 … But even that first one, I know I was crying before it happened because I had this, you know, "Oh, what if he has a reaction? Oh, this will be terrible."'

- Amy

3.4. The relationship between lifestyle and vaccination trajectories

Both the lifestyle and vaccination trajectories formed part of each parent's narrative of how they arrived at their current vaccination position. Fig. 3 illustrates that those who followed the *Never Have Vaccinated* trajectory were exclusively located in the *Consistently Alternative* and *Mainstream–to–Alternative* lifestyle trajectories. These parents' vaccination decisions appeared to be more often grounded in long-held beliefs rather than a specific experience. The remainder of the parents were distributed among all three lifestyle trajectories, and many reported an "initiating occurrence" that pushed them toward vaccine refusal. For some, this same occurrence also led them to pursue a more alternative lifestyle where Western medicine had failed them, for others the lifestyle changes preceded vaccine refusal. Whether that occurrence was vaccine-related or not varied, and the relationship between lifestyle and vaccination can only be considered related, not causal.

4. Discussion

This study provides insight into the journeys of parents who decide not to vaccinate their children, and how this journey may or may not continue to eventual vaccination.

Our findings challenge stereotypes often propagated in scholarly work and public discourse that all non-vaccinators follow a natural-health focused lifestyle and subscribe to alternative health beliefs (Attwell et al., 2018; Chambers, 2015; Elliott, 2019). The parents in previous studies appear to align with the *Consistently Alternative* and *Mainstream-to-Alternative* lifestyle trajectories we identified, but not the *Consistently Mainstream* lifestyle trajectory. This apparent divergence could be due to our sampling approach – other studies used locally-based snowballing recruitment in specific geographical areas known for low vaccination and people living alternate lifestyles. Our sample was geographically dispersed nationally and while some participants were recruited through snowballing, the majority were not connected with one other. This approach may have enabled us to identify a broader spectrum of health and lifestyle approaches among non-vaccinating parents.

Our results align broadly with the largely survey-based global literature on vaccine hesitancy, which points to it being a varied and context-specific continuum of attitudes (Peretti-Watel et al., 2015; Yaqub et al., 2014). Our study helps address a gap in this literature identified by Larson et al., who suggest that qualitative studies in all global regions would enhance understanding of vaccine decision-making (Larson et al., 2014). The novel contribution of our study is the elicitation of the processes by which Australian parents come to refuse vaccination in the context of newly mandated vaccination policy – a context important for international policy-makers looking to inform future approaches in their own jurisdictions.

As we showed, there were three trajectories that parents followed to arrive at their current vaccination position: The *Never Have Vaccinated* Trajectory; The *Changed Position Once* trajectory; and, the *Changed Position Twice* trajectory. How these trajectories commenced and progressed were in some cases intuitive, starting with a generalized doubt. For others their decision-making process started with a specific issue or an adverse experience, often coupled with feeling failed by the mainstream health care system. Common traits in the described trajectories included a fear-denial-abandonment-quest narrative, which was often

stressful and involved expending significant time and energy investigating vaccination, accessing a variety of sources including the peer-reviewed scientific literature. These findings reinforce similar experiences among a geographically clustered sample of non-vaccinating parents (Helps et al., 2019). Parents' diligence has also been described elsewhere (Attwell et al., 2018; Ward PR et al., 2017; Ward et al., 2017) and the activities of these parents align with the ideals of expending time and energy in the pursuit of intensive, conscientious parenting described by Hays and others (Hays, 1996; Lee et al., 2014).

We recommend future research focusing on the points along the vaccination trajectories where parents may be likely to shift their stance toward vaccination, particularly in relation to the fear-denial-abandonment-quest narrative.

In all cases, parents' vaccination trajectories were intertwined with mainstream and alternative lifestyle trajectories. While we identified three general pathways taken toward not vaccinating, these vaccination trajectories point to vaccination decisions as being complex, dynamic and highly individual in their detail and meaning to parents.

Commentators often argue that passively reading anti-vaccination messages online or otherwise is the sole cause of vaccine refusal. Contrary to this, many parents in our study had experiences that sent them on a quest for information, in which they had considerable agency. Hence, while they may have sought and processed negative messages about vaccination online, many did so critically, and this information did not solely shape their decisions, a finding supported by other international studies (Yaqub et al., 2014).

At the time of interview, parents were occupying one of two positions: either they were not going to vaccinate in the foreseeable future, or they had made moves to catch their child up with the national immunisation schedule. Of those who remained steadfast in refusing, there were two opposing views: either their child was robust enough to withstand the illnesses and the vaccines were therefore unnecessary, or their child was not robust enough to withstand the perceived assault on their body the vaccines would cause. For both sets of parents, stricter vaccination policies often served only to strengthen their resolve, a finding noted in previous research (Helps et al., 2018).

The parents who did vaccinate their children did so after very careful consideration, reporting the experience to be stressful. Those who did so in response to the legislative changes perceived a loss of their autonomy and control over their children's health, which contradicted a societal expectation to be responsible for one's child.

Our findings have implications for how health care professionals can engage with non-vaccinating parents and for vaccination policy. First, there is value in understanding these parents' stories. The complexity of the vaccination trajectories we observed, and the individual nuances of each parent's journey, are important aspects of their decision not to vaccinate. For some, an adverse experience led parents to feel dismissed by the medical establishment, and this became a significant landmark on the journey to vaccine refusal. Regardless of whether these were adverse events following immunisation or other health conditions, these parents' lived experiences of those events and the ongoing aftermath cannot be dismissed or understated. Nor can the resultant loss of trust in the health care provider and/or the broader medical system.

These findings, along with those of Helps et al. (2019), suggest that good management and communication around adverse events following immunisation is crucial and may prevent some parents from rejecting vaccination. More broadly, positive primary health care experiences with vaccination may engender resilience when people's trust in vaccination is tested.

A second emphasis is the importance of a respectful approach during clinical encounters with non-vaccinating parents, many of whom report difficult experiences in these consultations. This approach can involve asking about their stories, understanding the nuanced reasons behind their decision not to vaccinate, and acknowledging their experiences. Such an approach is likely to be more effective in fostering trust, and encouraging continued engagement with child health services, even if the parents continue to choose not to vaccinate. For those who choose to vaccinate eventually, a clinician may need to adopt ways to deal with potential anxiety for such parents and their children if they are vaccinating later than recommended. These findings have informed our work in supporting providers to have conversations with vaccine rejecting parents (Berry et al., 2018).

Further to this, our findings suggest that, contrary to the current discourse painting non-vaccinating parents as not aligned with our society's ideas of good parents, these parents are driven by the same values and priorities as most Australian parents, both vaccinating and non-vaccinating. Focusing on this common ground and engaging with them as 'parents' rather than 'non-vaccinators' may serve to create a more positive encounter with medical services, and further engender trust. In the public arena this applies to care with use of the term 'anti-vaxers', which we recommend reserving exclusively for activists, rather than all non-vaccinating parents.

It is also significant that Australia's imposition of financial penalties and bans from childcare made some of these parents more steadfast in their position. Our work contributes to a growing body of evidence on the potential effect of such policies on non-vaccinating parents (Betsch and Böhm, 2015; Helps et al., 2018). This intensifies the need for quantitative evaluation of how strict vaccination policies affect committed vaccine refusers, who are often their stated or implied target. Evidence from California, where personal belief exemptions were removed from state-based requirements, found a 'replacement effect' whereby parents committed to vaccine refusal sought other means of remaining unvaccinated (Delamater et al., 2019).

Our study has some limitations. While great care was taken to garner the thoughts of as many non-vaccinating parents as possible, recruitment for this study proved difficult. We experienced censoring of our recruitment advertising by online parenting groups who deemed the topic of vaccination too sensitive. Meanwhile, some of our paper posters in public places were defaced with profane or abusive messages, photos of which were then shared and 'liked' on social media. This censorship and polarizing discourse no doubt discouraged some parents from participating in our study. Further to this, we received feedback from a number of non-vaccinating parents that they did not trust our motives, believing we would use the information they shared to find ways to make them vaccinate their children. This means that while we are confident we were able to garner the views of a range of non-vaccinating parents to saturation, it is possible that we were not able to meaningfully include in our analysis the thoughts of 'silent' objectors who might have feared being identified by pro-vaccine activists, or activist non-vaccinators who might be more strident but mistrusted our motives.

5. Conclusion

Previous studies on vaccine refusers have been geographically based and focused on culturally-specific communities. This study was the first to engage with a cohort of geographically dispersed parents and focus specifically on variation in the social-psychological process of vaccinating or not-vaccinating one's children. Most parents are influenced by contemporary norms demanding intensive inputs into child development and well-being. For most parents, routine vaccination is an unproblematic feature of parenting. The parents in this study came under scrutiny because their parenting journeys have, by contrast, included temporary or ongoing vaccine delay or refusal. Drawing out the trajectories of these parents' experiences provides a salient reminder that a parent's current status regarding vaccination may not be their final destination. All interventions, from restrictive vaccination policies to empathic clinical conversations, can benefit from better understanding parents' commitment to their children's health, how their experiences lead to their positions and, in some cases, their steadfastness in maintaining them.

Author contribution statement

Kerrie E Wiley: Investigation, Formal analysis, Writing – original draft, Writing – review & editing , Visualization, Project administration. Julie Leask: Conceptualisation, Methodology, Writing – review & editing, Supervision, Funding acquisition. Katie Attwell: Formal analysis, Writing – review & editing. Catherine Helps: Formal analysis, Writing – review & editing. Chris Degeling: Formal analysis, Writing – review & editing, Funding acquisition. Paul Ward: Formal analysis, Writing – review & editing, Funding acquisition Stacy M Carter: Conceptualisation, Methodology, Formal Analysis, Writing – review & editing, Supervision, Funding acquisition.

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Declaration of competing interest

The Authors have no interests to declare.

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