Social Science & Medicine 196 (2018) 106–114

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

"Do-it-yourself": Vaccine rejection and complementary and alternative medicine (CAM)

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ARTICLE INFO

Keywords:
Vaccination
Vaccine hesitancy
Immunisation
Complementary and alternative medicine
Epistemology

ABSTRACT

In this article, we elucidate a symbiotic relationship between complementary and alternative medicine (CAM) and rejection of, or hesitancy towards, vaccination. In Fremantle, Western Australia, and Adelaide, South Australia, we conducted in-depth interviews from September 2013–December 2015 with 29 parents who had refused or delayed some or all of their children's vaccines. Our qualitative analysis found that for many, their do-it-yourself ethic and personal agency was enhanced by self-directed CAM use, alongside (sometimes informal) CAM practitioner instruction. Reifying 'the natural,' these parents eschewed vaccines as toxic and adulterating, and embraced CAM as a protective strategy for immune systems before, during and after illness. Users saw CAM as harm-free, and when it came to experiences that non-users might interpret as demonstrating CAM's ineffectiveness, they rationalised to the contrary. They also generally glossed over its profit motive. CAM emerged as part of an expert system countering Western medicine. CAM's faces were trusted and familiar, and its cottage capitalism appeared largely free from the taint of "Big Pharma." A few parents employed a scientific critique of CAM modalities – and a minority were dubious of its profit motive – but others rejected the epistemology underpinning biomedicine, framing CAM as a knowledge not poisoned by avarice; a wisdom whose very evidence-base (anecdote and history) was demeaned by an arrogant scientific process only permitting belief in that which could be quantified. However, all parents engaged with Western medicine for broken bones and, sometimes, medical diagnoses. Our analysis suggests that pro-vaccination health professionals, policymakers and information-providers seeking to address the role of CAM in vaccine rejection face significant challenges due to the epistemic basis of some parents' decisions. However, we make some suggestions for professional practice and policy to enhance trust in vaccination.

1. Introduction

Acceptance of vaccination is a major driver of uptake, along with issues of access, affordability and awareness. Non-acceptance of vaccination is a phenomenon that concerns global agencies. In 2012, a World Health Organisation (WHO) working group was formed to address vaccine rejection – named 'hesitancy' – recommending expanded research to capture factors at individual, community, contextual and organizational levels (World Health Organisation, 2014). One factor that interrelates with individuals' vaccine rejection is use of complementary and alternative medicine (CAM) (Eve Dube et al., 2013; Wardle et al., 2016). A national survey of Australian parents found that obtaining information from alternative health practitioners was strongly associated with self-reported non-compliance with the vaccination schedule (Chow et al., 2017). However, despite an unequivocal correlation, there has been little research that probes or challenges assumptions about causality in either direction. Causality may be obscured due to confounding factors; for example, income, education, and distrust of the medical system are associated with both CAM use and vaccine rejection (Gaudino and Robison, 2012; Wardle et al., 2016). So, too, are high levels of agency and autonomy (Browne et al., 2015; Ernst, 2001). How, then, can we best understand the relationship between CAM use and vaccine hesitancy or rejection? How might this inform action by government, policymakers and health professionals who seek

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https://doi.org/10.1016/j.socscimed.2017.11.022
Received 4 May 2017; Received in revised form 15 November 2017; Accepted 15 November 2017
Available online 16 November 2017
0277-9536/

to address the latter via policy, practice or campaigns? This paper addresses this knowledge gap by exploring how vaccine rejecting and hesitant parents in two Australian cities present their use of CAM *vis a vis* their vaccination decisions.

Wardle et al. define complementary medicine as 'a diverse group of healthcare practices not generally considered part of the conventional medical curriculum' (2016, 2). Their literature review explored modalities including (but not limited to) acupuncture, aromatherapy, Chinese medicine, chiropractic, homeopathy and naturopathy. Pedersen (2013) describes alternative medicine as 'treatment not usually offered within the ordinary health service and without public support or control, but offered on a fee-for-service basis by non-authorised practitioners with varying types of training and certification.' (p.56). While Pedersen's definition makes a useful reference to the political economy of CAM – to which we will return – it is restrictive in focusing only on delivery by practitioners. By contrast, Wardle et al. (2016) distinguish between CAM as employed under the guidance of a specific practitioner, and CAM as self-prescribed and utilised, paying attention to both. The Cochrane collaboration definition extends to considering "accompanying theories and beliefs" that travel with "healing resources" outside the "politically dominant health system" (Zollman and Vickers, 1999, 693). We employ a very broad definition to describe both the modalities of specific practitioners and parent-directed use of supplements and traditional remedies. We focus specifically on parental perceptions and experiences of CAM, whilst recognising that parents undertake a much wider variety of activities to promote the health and wellbeing of their children. Finally, although CAM and biomedicine are distinct paradigms (or, as we will go on to characterize them, part of distinct expert systems), CAM is often a supplemental form of health care, rather than an alternative; many CAM users also use biomedicine (Browne et al., 2015; Stokley et al., 2008). An Australian study found that 69% of a representative sample had visited a CAM provider in the last 12 months (Xue et al., 2007), yet we know from Australia's vaccination coverage of 93% that most of the parents amongst this sample would still be vaccinating their children. Nevertheless, Australian data clearly shows that seeking vaccination information from CAM providers makes parents more likely to be vaccine hesitant or refusers (Chow et al., 2017), hence the relationship invites deeper analysis.

A spectrum of vaccine acceptance extends from active demand and full vaccination to complete rejection of all vaccines. Vaccine hesitancy falls in the middle, where people may experience doubt and uncertainty and either fully or partially vaccinate. Parents in this study range from vaccine hesitant to vaccine rejecting. In a previous paper, we analysed how such parents view and (dis)trust expert systems pertaining to vaccination. This amounted to, in many cases, a rejection of Western medical epistemology itself and, consequently, some or all vaccines (Attwell et al., 2017). This article explores the flipside of this. Intimate with parents' *distrust*, we instead seek to understand their trust in alternative modalities. Accordingly, we have reanalysed the data to investigate how and why parents used CAM, why they considered it beneficial or trustworthy (unlike Western medicine) and how – if at all – they digested the notion that CAM, like pharmaceutical companies, operates for-profit. We explore these factors in relation to individual parents' rejection of some or all scheduled vaccines.

2. Methods

Data were collected in Fremantle, Western Australia (WA) and Adelaide, South Australia (SA). The data arose from the collation of two, originally independent qualitative research projects, conducted by researchers who subsequently joined forces after identifying common project aims and methods (during the final phase of data collection in SA). Both studies employed semi-structured interviews with parents who were not vaccinating, partially vaccinating or had delayed some vaccinations for their children. All participants' reasons related to personal choice rather than access, practical or logistic barriers. Among other site-specific questions, both studies explored perceptions of vaccinations, vaccine preventable diseases, healthcare professionals and social systems, with a specific focus on factors influencing parents' decisions. All parents were asked about vaccine related information sources, family attitudes and their social milieu. In-depth, face-to-face interviews of more than an hour provided rich accounts of parents' specific views, experiences and practices. Participants were incentivised with a $25 gift card (WA) and $30 cash (SA) and are referenced here with pseudonyms.

Fremantle parents were interviewed by the lead author between September 2013 and April 2014 from postcodes surrounding the City of Fremantle, which at the time recorded full vaccine coverage rates at below 87 per cent for children under five, compared to the Australian average of just over 90 per cent (National Health Performance Authority, 2014). Parents with a child aged five or under were recruited through posters, newspaper advertisements, social media and snowballing, and screened to meet inclusion criteria of delay or refusal of recommended vaccines. Where possible, WA parents were interviewed twice – before and after a local vaccination social marketing campaign – but this was only possible for half the sample; one declined to be re-interviewed and three were recruited later. Adelaide (SA) parents were interviewed by PR once between October and December 2015. PR approached potential participants at a suburban organic market and organised initial interviews. On completion of interviews, which took place mainly in their homes, PR asked participants to share information leaflets within their social networks. The snowballed participants subsequently contacted PR, who were screening to check they had delayed or refused vaccination for their children. At both sites the informal snowballing method was a challenge for documenting self- and criteria-based exclusion. Researchers had aimed for 10 participants in WA and 20 in SA with these figures almost reached (9 and 20). The University of Western Australia and Flinders University Social and Behavioural Research Ethics Committee provided ethical approval for the projects under permit RA 4/1/5890 and project number 6976 respectively.

Four differences between the research sites and studies affected the data; points two and three will be revisited. Firstly, WA parents were screened on whether they identified themselves as 'alternative lifestyle', while the SA individuals were not asked this, but were recruited predominantly through an organic market. Secondly, WA parents were asked another screening question to rule out those who identified as anti-vaccination, whereas the SA sample included several parents who rejected all vaccines. On this basis, the SA sample was a broader spectrum covering hesitant parents to anti-vaccination campaigners, while WA parents were more towards the hesitant/fence-sitter middle of the spectrum. Thirdly, while some SA interviews probed for CAM use and trust, CAM emerged spontaneously in WA both as a source of trust and distrust. The fact that CAM was a significant feature in both sites justified the re-examination of relevant data. Fourthly, but less significantly, while initially targeting parents of young children, those with older primary-school age children were later included in SA, skewing the age of participants *vis a vis* WA participants.

The lead author (WA) and research assistants (WA and SA) transcribed the interviews verbatim. Following in-depth reading, the lead author developed an initial coding tree using QSR International's NVivo 10 Software. A broad CAM node was broken down to explore specific theoretical insights arising from the literature exploring the relationship between trust and CAM, notably the work led by Pedersen (2013; Pedersen and Baarts, 2010; Pedersen et al., 2016). This way, we extracted data elucidating current theories and also generated new insights. Transcripts of participants who reported distrust in aspects of CAM were reviewed with the aim of identifying differences between them and CAM users, with attention paid to all parents' vaccine trajectories. Frequent discussions within the research team guided coding and recoding. This involved developing a visual representation of vaccination expert systems (as constructed by participants) that would