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"Everybody just wants to do what's best for their child": Understanding how pro-vaccine parents can support a culture of

³ vaccine hesitancy

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ABSTRACT

Background: Although a large majority of parents vaccinate their children, vaccine hesitancy has become more widespread. It is not well understood how this culture of vaccine hesitancy has emerged and how it influences parents' decisions about vaccine schedules.

Objective: We sought to examine how attitudes and beliefs of parents who self-report as pro-vaccine are developed and contribute to immunization decisions, including delaying or spacing vaccines.

Methods: Open-ended, in-depth interviews (N=23) were conducted with upper-middle class parents with young children living in Philadelphia. Interview data were coded and key themes identified related to vaccine decision-making.

Results: Parents who sought out vaccine information were often overwhelmed by the quantity and ambiguity when interpreting that information, and, consequently, had to rely on their own instinct or judgment to make vaccine decisions. In particular, while parents in this sample did not refuse vaccines, and described themselves as pro-vaccine, they did frequently delay or space vaccines. This experience also generated sympathy for and tolerance of vaccine hesitancy in other parents. Parents also perceived minimal severe consequences for deviating from the recommended immunization schedule.

Conclusion: These findings suggest that the rise in and persistence of vaccine hesitancy and refusal are, in part, influenced by the conflicts in the information parents gather, making it difficult to interpret. Considerable deviations from the recommended vaccination schedule may manifest even within a provaccine population due to this perceived ambiguity of available information and resulting tolerance for vaccine hesitancy.

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1. Introduction

The 2014-2015 measles outbreak, in which 129 people from 7 23**03** states in the US were reported to have measles linked to Disneyland 24 in California, has highlighted the resurgence of vaccine-preventable 25 childhood diseases previously all but eliminated in the US by the 26 27 implementation of the routine child immunization schedule [1,2]. While nationally the coverage of measles vaccination is high [3], 28 the resurgence of measles, with 668 cases in 2014 and 178 in 29 2015 as of June, points to the risk of social or spatial clusters of 30

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http://dx.doi.org/10.1016/j.vaccine.2015.10.090 0264-410X/© 2015 Published by Elsevier Ltd. undervaccinated children [1,4,5]. It also sheds light on rising parental vaccine hesitancy and refusal in the United States, as evidenced by increasing exemptions from mandated immunizations for school-entry and parental requests for alternative childhood immunization schedules [6–10].

Parental vaccine decision-making has been studied extensively to understand vaccine hesitancy and alternative vaccination schedules [8,11–17]. Nationally, coverage for most childhood vaccines is high, indicating that most parents choose to vaccinate children [3]. However, more and more concerns are being raised about the safety of the immunization schedule given controversies about the connection between vaccines and autism, the ingredients in vaccines, and the number of injections given to children [11]. A 2010 survey given to a random sample of households found that while the majority of parents intended to vaccinate their children, most of them also had questions or concerns about vaccines [11]. A 2009 study of health care providers

Abbreviations: ACIP, Advisory Committee on Immunization Practices; MMR, Measles-Mumps-Rubella.

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Table 1

Interview guide.

Introduction to the interview

IGeneral parental beliefs about and approaches to child health

- Tell me a little about your child(ren).
- \bigcirc Any main health/medical issues with your child(ren)?
- Tell me a bit about the last time you made a decision about your child's health?
- \bigcirc What was the issue?
- \bigcirc Talk though how you made the decision.
- \bigcirc How did you feel about the decision you made?

Parental vaccine decision making

- Free-listing: List all of the words that come to mind when you hear the word "vaccine." Please try to give one word answers.
- Among the parents you know who do vaccinate their children, what reasons do they give for vaccinating?
- Among the parents you know who do not vaccinate their children or pursue an alternative schedule, what reasons do they give for that decision?
- Did vou decide to vaccinate vour child or children? Tell me about it.
- When did you start thinking about vaccination?
- What prompted you to start thinking about vaccination?
- What sources of information did/do you seek out? Why did you use those sources?
- \bigcirc What was important to you in making the decision?
- Tell me about some conversations you've had with family or friends about vaccination.
- O How do your feelings about vaccination compare with those of your partner/spouse? How do your feelings about vaccination compare with those of your friends?
- What messages about vaccination did/do you hear from the media?
- \bigcirc Have you changed your mind about vaccinating since your child was born? Tell me about that.
- What sorts of information or experiences might make you think differently about your vaccine decisions?
- Is there anything else you'd like to mention?

Marental choice of medical provider

- How did you end up with your current doctor or pediatrician?
 - Has your child ever seen a different primary care provider regularly? How did you end up switching?
- What was important for you in choosing a doctor?
- How do you feel about your child's doctor as a source of information and advice about health?
- O How important is it to you that your doctor share your views on child health issues that are important to you?
- \bigcirc How important is it to you that your friends go to or recommend your doctor?
- O What would you do if you had a disagreement with your doctor about an important health issue?

Vnterview wrap up

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found that 43% and 28% of physicians thought parents' level of concern about vaccines had greatly or moderately increased, respectively, compared to five years before [7]. These doubts manifest themselves on a spectrum of vaccine decision-making that may then lead to deviance from the recommended Advisory Committee on Immunization Practices (ACIP) immunization schedule [12.18].

A number of studies have found that common reasons for forgoing or delaying vaccines include: concern about vaccine safety or efficacy; the necessity of vaccines; the perception that the child was too young; or the child being sick [14,16,19]. Common parental concerns about vaccinations include child's pain or anxiety during immunization; short-term side effects of immu-60 nization; vaccine safety; immune system overload; and number of vaccines received [15]. However, external factors also mediate vaccine concerns and behavior. Studies show that trust in the doctor is an important factor in parents' confidence and decision to vaccinate [12,20]. Furthermore, immunization decisions are influenced by social norms and by the behavior and attitudes of peers [11,21,22].

The vast majority of parents continue to vaccinate their children according to the ACIP-recommended schedule, suggesting belief in the benefits of vaccination and trust in the advice from health care providers. However, vaccine hesitancy and questions about the instituted immunization schedule have become more common as parents continue to raise doubts and concerns about vaccines. In this context, the goal of the current study is to 74 understand how parents make vaccination decisions, how their 75 vaccine concerns translate into deviations from the ACIP schedule 76 despite general acceptance of vaccines, and how they view oth-77 ers' decisions not to vaccinate. Elucidating these phenomena can 78 help explain the rise in and persistence of vaccine hesitancy and 79 refusal that have contributed to events like the Disneyland measles 80 outbreak.

2. Methods

2.1. Participants and data collection

This qualitative study used semi-structured interviews to understand how parents make decisions about child vaccination, and the attitudes, perceptions and beliefs underlying these decisions. We used convenience sampling to recruit parents in an upper-middle class neighborhood in Philadelphia. We chose this neighborhood for three reasons: (1) the relatively high socioeconomic status meant that at least some parents would be likely to report vaccine hesitancy or refusal [16,23]; (2) the neighborhood is served by a pediatrician who accommodates alternative vaccine schedule requests and with whom we had conducted clinic-based studies [24]; and (3) an active neighborhood parent listserv facilitated recruitment. We did not target parents based on vaccine behavior. A total of 23 interviews were conducted by two of the authors (YB, AB) between July and September 2010, a year with a particularly large number of pertussis and mumps cases [25]. 25 participants (19 mothers and 2 couples) who had at least one child aged 18 months-6 years and were living in Philadelphia were interviewed. Participants provided written consent to audio-record the interviews and provided their age, educational attainment, race-ethnicity, zip code of residence, and birth year of child(ren). Interviews lasted an average of 35 min. Participants were given a \$20 gift card to a local natural foods supermarket as a thank you. This study was approved by the Institutional Review Board of the University of Pennsylvania.

The goal of the interview was to elicit a narrative about parental experiences of vaccination and vaccine-related decisions. The interview guide (see Table 1) consisted of open-ended questions about their child's health and temperament; a recent health-related decision; the decision process around child vaccination, including information gathering, discussion with others, and interactions

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