A qualitative study on parents’ reasons and recommendations for childhood vaccination refusal in Malaysia

Jolyn Rumetta a, Haureen Abdul-Hadi b,*, Yew-Kong Lee b

a Family Health Development Division, Ministry of Health, Block E10, Complex E, Pusat Pentadbiran Kerajaan Persekutuan, 62590 Putrajaya, Malaysia
b Department of Primary Care Medicine, Faculty of Medicine, University of Malaya, 50603 Kuala Lumpur, Malaysia

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ABSTRACT

Background: Vaccine-related diseases are increasing in developing countries. This study aimed to explore parents’ reasons for refusal of childhood vaccinations in Malaysia and their recommendations on addressing their concerns.

Methods: A qualitative study design involving individual both face-to-face and online in-depth interview was used. The topic guide was developed from the Health Belief Model theoretical framework. Seven face-to-face and seven online interviews were conducted with parents in the Klang Valley (an urban area) who had refused childhood vaccination. All interviews were audio-recorded, transcribed verbatim and checked. Thematic approach was used to analyze the data. Data was collected until data saturation was reached.

Results: Findings were summarized into two main categories: Personal Health Beliefs and Vaccine Related Concerns. Six personal health beliefs were identified: lack of confidence in modern medicine and health care personnel, pharmacetical conspiracy to sell medicines, preference to a natural approach to health, personal instincts, religious beliefs and having a partner with similar beliefs. Four main vaccine-related concerns were identified: negative effects and content concerns, doubts of necessity and lack of information and knowledge regarding vaccines. Parents recommended that more empathy from healthcare professionals and evidence on safety and content purity would help them reconsider vaccination.

Conclusion: Parents had multiple reasons for refusing childhood vaccinations but felt that communication and empathy from healthcare professionals was lacking. Besides individual consultations with parents, addressing these concerns at multiple levels in the health care system and society may help to increase the uptake of childhood vaccinations in the future.

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Introduction

Vaccination programs are among the greatest and most effective public health interventions in preventing morbidity and mortality caused by infectious diseases, second only to clean water [1]. However, vaccine preventable diseases (VPDs) are making a comeback due to parental vaccine refusal. Studies on vaccine refusal in the US have reported that these refusals are often clustered in specific communities, indicated by the higher prevalence of VPD outbreaks in these groups [2]. Concerns have been raised about the increase in vaccine-preventable diseases in Muslim-majority communities such as Malaysia [3]. Reasons for vaccine refusal may vary between communities and it is important to understand and address these reasons.

Malaysia is a multi-cultural, Muslim-majority, developing middle-income country with a public healthcare system. Vaccinations are free and coverage was as high as 97–99% for BCG and DTP vaccines in 2014 [4]. However, vaccine refusal is fast increasing [3]. Malaysian Ministry of Health (MOH) officials stated that cases of parents who refused vaccinations increased from 470 cases in 2013 to 1541 in 2015 [5,6]. This has led to a resurgence of VPDs; there was a reported 3-fold rise in the cases of measles in 2015 with 50–60% of these among unvaccinated children [7]. A survey among urban Malaysian parents with children reported that vaccine hesitancy was about 10% and was associated with mothers expecting their first child and unemployment status [8].

In 2016, following five deaths and twenty-five confirmed cases of diphtheria, a growing backlash against the anti-vaccination
movement was given widespread media attention [5,9]. This lead to parents who refuse vaccinations avoiding detection due to fear of being ‘hunted down’ which could make them reluctant to discuss anti-vaccination views in consultations.

Study aim

This study aims to explore Malaysian parent’s reasons for vaccine refusal and to report their views on recommendations on discussing their vaccine-related concerns. Findings from this study will shed light on the growing trend of anti-vaccination in developing countries and help healthcare professionals (HCPs) discuss vaccine refusal with parents from these regions.

Methodology

A qualitative approach was taken in this study to enable exploration of the factors that influence parents’ decisions not to immunize their children. In-depth interviews (IDIs) were conducted in two ways: face-to-face interviews and online messaging service interviews (Facebook Messenger). The online interviews were conducted for participants who requested convenience and privacy. Furthermore, the internet has been reported as the primary source of vaccine information in Malaysia [8]. Each participant received RM50 (USD 12.50) as a reimbursement for their time and/or travel. Ethics approval was obtained from The University of Malaya Medical Ethics Committee (UMMC MEC ID.NO: 20156-1444).

Participants and setting

Participants were recruited via purposive sampling and snowballing. They were recruited by physicians at the Primary Care Clinic in University of Malaya, through friends and relatives as well as online communities. The inclusion criteria were parents who refused any type of childhood vaccination and resided in Klang Valley. Interviews were conducted over a period of 16 weeks between 1st September to 31st December 2015. A topic guide was developed based on the constructs of the Health Belief Model and used to guide the interviews. Face-to-face IDIs lasted half-an-hour to one hour whereas online interviews lasted up to eight hours as they were interrupted by pauses and breaks. Recruitment was stopped when data saturation was reached which determined the sample size.

Analysis

All interviews were transcribed verbatim and checked for accuracy. The data from the interviews were analyzed using NVivo10. Three researchers used a thematic analysis approach for data analysis, based on Strauss and Corbin’s method of open, axial and selective coding to develop an initial coding framework [10]. Subsequent interviews were coded by the main researcher. Regular meetings were held to evaluate the content and structure of the emerging coding framework and any discrepancies were resolved through discussion.

Results

A total of 14 participants were interviewed at which point data saturation was reached (Table 1). From the seven participants of the face-to-face interviews, there were five Malay mothers, one Chinese mother and one Indian father. The online interview participants were all mothers: two Malays, two Indians and three Chinese. All participants had received tertiary education.

Table 1

<table>
<thead>
<tr>
<th>Demographic</th>
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<tbody>
<tr>
<td>Age (mean, range), years</td>
<td>37.4 (28–49)</td>
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<tr>
<td>Gender</td>
<td></td>
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<tr>
<td>Female</td>
<td>13</td>
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<tr>
<td>Male</td>
<td>1</td>
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<tr>
<td>Ethnicity</td>
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<tr>
<td>Malay</td>
<td>7</td>
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<tr>
<td>Chinese</td>
<td>4</td>
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<td>Indian</td>
<td>3</td>
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<tr>
<td>Education level</td>
<td></td>
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<tr>
<td>Diploma</td>
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<tr>
<td>Degree</td>
<td>12</td>
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<tr>
<td>PhD</td>
<td>1</td>
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<tr>
<td>Number of children (mean, range)</td>
<td>2.6 (2–6)</td>
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</table>

The findings of this study could be divided into reasons for vaccine refusal, sources of information, and recommendations for uptake. A summary of the findings is given in Table 2.

The reasons parents refuse vaccination for their children found in this study can be divided into two main categories: personal health beliefs, and vaccine-related reasons.

Personal health beliefs

Parents expressed a range of health beliefs which played an important role in motivating them to refuse vaccination. These beliefs involved their belief of health and illness, attitudes to health services and views of a disease. Six categories of personal health beliefs identified among our participants which influenced their decisions about vaccination:

Lack of confidence in modern medicine and distrust of health care personnel

Participants expressed their lack of confidence in modern medicine and health care personnel, particularly doctors.
Participants believed modern medicines did not cure or treat diseases; as one participant said:

“Western medication does not heal permanently. They don’t heal the root cause.” (Mrs. SM/F/38/online).

Participants who believed this had past experience using modern medication which did not cure their illnesses: “So we went to the doctors many times and the doctor’s medicine would not help at all. But we would keep on eating the medicines. ...the antibiotics and all” (Mrs. LW/F/40).

As participants viewed vaccines as modern medications, they believed that vaccines were also ineffective in preventing diseases.

**Pharmaceutical conspiracy**

Some participants believed that vaccines are manufactured by pharmaceutical companies for their own profitable gains and not for the prevention of diseases. They believed these companies were in collusion with doctors who marketed vaccines for monetary gain.

“Well the pharmaceutical companies wanting to make money. All these so called convenience of creating the so called 6 in 1 jab is crazy” (Mrs. MY/F/online)

**Natural approach to health and immunity**

Participants practiced an approach to health that was described as “natural”; this meant avoiding ‘unnatural’ man-made medications such as vaccinations. Substances that are viewed as unnatural were believed to be unnecessary; the argument was that the human body was not made to be dependent on them to function normally.

“I believe that when a child is born that we should be as natural as possible. We don’t want to put things in our body that are not natural.” (Mrs. LW/F/40)

These participants also believed that immunity that was obtained through contracting the disease was better than vaccine-induced immunity as it would last longer and was a stronger type of immunity.

“I think it’s better to obtain the immunity naturally by falling sick” (Mrs. JC/40/F/online)

**Religious beliefs**

Participants argued from design that if God created humans to withstand diseases by giving them an immune system, then vaccines were unnecessary:

“Another one is my belief if God created us you know. Human beings... when there is no disease yet... why do we need vaccine?” (Mrs. LW/F/40).

**Instincts**

Two participants mentioned that their decisions were made based on their instincts. Instincts were described as a gut feeling that they should not vaccinate their children. “I make decision sometimes also... I make decision sometimes also is just my instinct.” (Mrs. LW/F/40)

**Partners with similar beliefs**

Most participants had made the decision not to vaccinate jointly with their partners. Having partners who also refused vaccination reinforced their decision to refuse vaccination for their children:

“Yes...yes... we made the decision together after what happened to A... We are supportive of each other. I’m grateful for that” (Mrs. MY/F/40/online)

**Vaccine related reasons**

Most participants refused vaccines for their children due to factors related to the vaccine itself. In this study we found four factors related to vaccines that influenced participants’ decision to refuse vaccination:

**Negative health effects of vaccines**

Almost all participants were concerned about the negative health effects of vaccines. Many strongly believed that vaccines came with multiple short-term and long-term side effects that were potentially life-threatening. Some of the negative effects mentioned were the development of asthma, eczema, autism and even brain injury.

The term AEFI (Adverse Events Following Immunization) was used by certain participants. This was defined as any untoward medical occurrence which follows immunization and which does not necessarily have a causal relationship with the usage of the vaccine. The adverse event may be any unfavorable or unintended sign, abnormal laboratory finding, symptom or disease. The following quotes illustrate how the participants’ own experiences and their children’s experiences had influenced the participant’s decision on not to vaccinate.

“Yes yes...personally... when I was young... I developed allergic reaction to tetanus vaccine” (Mr. MK/M/32)

“To me, my main concern is aefi. I saw what happen to my step son (asthma and obesity) so idont want to risk my children” (Mrs. AS/F/38/online)

**Vaccine contents**

Participants were concerned regarding the contents of the vaccines. Concerns were from religious as well as health perspectives. Muslim participants expressed their concerns on the ‘non-halal’ (Islamic religious impurity) contents of vaccines which prevented them from vaccinating their children despite approval on the usage of the vaccines by religious authorities [11].

“...tak halal kan, vaccine nimemangtak halal, dah sahharitu. KKM pun dah keluar. Vaccine yang halal, 2017 nantibaruada.” (Vaccines are not “halal”, it’s confirmed. Ministry of Health has confirmed it. Halal vaccines will only be available in 2017.) (Mrs. NS/F/28)

Another concern was toxic contents like mercury and aluminum that were potentially harmful. One participant whose daughter was diagnosed with cerebral palsy at two months was convinced the heavy metals in the vaccine were the cause of it: “High level of heavy metal in a 2 year old body (After vaccination). And the sudden stiffness of her body” (Mrs. MY/F/40/online).

Others mentioned that impurities such as animal and aborted fetus cells were used in the production of vaccines. They felt this was dirty and unacceptable for their children:

“the method they use I don’t know some I read the method they use from like a monkey or animals they use from dirty the dirty things itself” (Mrs. MZ/F/36)

**Doubts on necessity of vaccines**

Participants believed vaccines were unnecessary as they were ineffective, that the diseases they prevented were curable and that VPDs were not a threat anymore.

“Her (a friend) son was always sick. And gotten almost everything he was vaxxed for Measles, chicken pox, whooping cough etc” (Mrs. LYY/F/40/online)

“Diseases are mostly eradicated because of improve sanitations, better sewerage system. Cleaner living condition, knowledge of nutrition.” (Mrs. LYY/F/40/online)
Lack of information, knowledge and understanding of vaccines

Some participants felt they lacked sufficient knowledge and understanding of vaccines to be giving them to their children. They were aware of the need to learn and gain more information about vaccines but lacked the time to do so. One participant was too busy with other commitments and said “I feel I need to know more, and it’s my job to know more, but I don’t have time at the moment. Too much work” (Mrs. LW/F/40).

Furthermore, most participants felt health care providers did not provide them with sufficient information regarding vaccines: “There is no explanation as what kind of (vaccine). They just tell you that. . . this is vaccine and we are going to do it. So there is actually no explanation and what is it for. . . this kind of vaccine, we actually don’t know” (Mrs. LW/F/40).

Sources of information

Participants obtained anti-vaccination information from various sources. We categorized the six sources into two groups: informal sources with mostly peer-to-peer content (internet websites, online groups, and friends and family) and formal sources with more authoritative (or even medical) content (doctors, books and public forums on vaccination).

“Oh I have also read this book how to have a healthy child. . . in spite of your doctor by Robert Mendelsohn. He advocate no vax n homebirth”. (Mrs. LLY/F/40/online)

“And even her doctor said since she’s brain injured, better not to vaccine her further” (Mrs. MY/F/40/online)

“I don’t remember the event name, it was meant to give awareness on the importance of vaccine. I never knew about AEFI until I attended the talk. Then everything made sense to me” (Mrs. AS/F/38/online)

Recommendations regarding vaccine uptake

Although most participants were firm with their current decision, some had suggestions on what might make them reconsider vaccination. Participants listed vaccine-safety related and vaccine dose suggestions. Vaccine safety had to be guaranteed through adequate testing and research, until “doctors can give the assurance that it is 100% safe” (Mrs. AS/F/38/Online), failing which authorities should “provide lifelong compensation for those who are adversely affected by vaccine” (Mrs. AS/F/38/Online). Muslim participants suggested that “Malaysia is an Islamic country . . . why not make their own vaccines that is halal” (Mrs. NS/F/28). One participant preferred to avoid combination vaccines: “in the old days, the inoculation was very simple, unlike today’s methods- too many in one vial” (Mrs. JC/F/42).

Some commented on HCP communication and hoped HCPs would be more helpful and open when providing information and discussing vaccine choice.

“If . . . if . . I know that the threat is for sure, if have more information on it (vaccines) and if I know that people that selling it is really not for money per se but humanity, you know, for the betterment of the world” (Mrs. LW/F/40).

They urged HCPs to be more empathetic, less judgmental as well as to respect their decisions.

“I understand how medical professionals are concern and passionate about getting every child vaxxed, but I wish they would look at the other side of the coin that is us: Parents with brain-injured child (following vaccination)” (Mrs. MY/F/40/online)

Discussion

Reasons for parental refusal in the Klang Valley and the sources of information regarding vaccines could be divided into two broad themes, personal health beliefs and vaccine related reasons.

This study revealed that many participants had a range of misconceptions about vaccines such as the side-effects, unclean content and pharmaceutical conspiracy. This misinformation was made worse because of both ‘pull’ (parents never asked doctors for information) and ‘push’ factors (doctors did not check if parents wanted more information before administering vaccines). HCPs are the cornerstones of vaccine confidence for patients and adequate HCP knowledge and positive regard for vaccines have been shown to be associated with increased vaccine coverage for nurses [12]. As suggested by the participants, an empathetic approach would facilitate the counseling process and may increase the vaccine uptake among these parents if the lack of knowledge and vaccine confidence is adequately addressed.

Some participants in this study lacked trust and confidence in health care personnel especially doctors. Studies elsewhere report an association between a lack of trust in HCP with parental refusal of vaccination [13,14]. In Malaysia, a lack of trust is surprising as Asian hierarchical culture traditionally esteems doctors’ views [15]. A likely explanation is the emergence of the internet as a source of heterogeneous information. Malaysia has one of the highest rates of Internet connectivity in the region at over 65% of the population [16] and a study has reported that the internet is the primary source of vaccine-related information for Malaysian parents [8]. Internet discourse inhabits a post–modern space where everyone is considered an ‘expert’, thus a purely educational model using traditional scientific legitimacy claims is unlikely to succeed at combating vaccine misinformation [14]. Rather, understanding and openly acknowledging the ideologies underlying anti-vaccination beliefs (e.g. choosing a natural lifestyle in this study) are important to initiate effective dialogues in patient-doctor consultations.

A finding that was similar to this study with other reports from Muslim-majority countries was the concern among participants of the vaccines containing “non-halal” substances [3]. This was despite the vaccines receiving “halal” status by the local religious authorities [11]. This concern has not been addressed adequately in literature or local public health vaccination programs. Since the issue is one of religious belief, it requires the involvement of authoritative religious bodies. For example, the Islamic Medical Association of Malaysia, a body representing Muslim HCPs in Malaysia, issued press statements on the religious legitimacy of vaccines [17] while state religious councils issued general vaccine guidelines [11] and also halal assurances on specific vaccinations such as diphtheria [18].

There are some limitations to the study. All participants in this study had a background of tertiary education and this study may lack the reasons lower-educational status parents refuse vaccination. The findings of this study are not generalizable as the sample was limited to a small group of parents in an urban setting. In the future, more research should be conducted to measure the prevalence of anti-vaccination practice and factors influencing this practice among the larger population, including those from a rural background.

Conclusion

This study provides an insight on reasons of parental refusal of childhood vaccination, sources of information and parent recommendations regarding vaccination in Malaysia. Acknowledging and addressing these concerns is important when counseling parents who refuse vaccination. The ability to build a trusting relationship

and further strengthen HCP’s knowledge and advice on vaccine would further facilitate the process with these parents.

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**Competing interests**

None declared.

**Ethical approval**

Not required.

**References**