

## Autonomy and Control among Parents Who do not Comply with Recommended Pediatric Vaccinations: A Qualitative Case Study

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### Abstract

**Objective:** To identify the main reasons why parents decided not to vaccinate their children according to the official recommendations.

**Methods:** A qualitative descriptive study approach was used, including 12 in-depth interviews with parents of two-year-old children who refused to vaccinate their children. Data were analyzed in three stages: open coding, mapping analysis and focused analysis.

**Results:** Five main themes emerged: Parents demand the right to make decisions regarding their child's vaccinations autonomously; they wish to take responsibility and be in control of their child's health; they perceive their actions (refusal) as characteristic of "good parenting"; they are critical of and distrust the medical establishment; and they base their decision on a calculation of the risks of the vaccines vs. the risk of the disease. Any combination of these factors may reflect the reasons for not complying with recommended pediatric vaccinations.

**Conclusion:** Parents' decisions whether, when and how to vaccinate cannot be ascribed to one single reason or cause; rather, it is a combination of interrelated factors. Understanding this complex phenomenon may help professionals plan interventions, to prevent a decline in vaccine coverage rates.

**Keywords:** Autonomous decision making; Childhood vaccinations; Perception of control; Public health policy

### Introduction

Vaccines are a common form of modern technology used worldwide and one of ten notable public health achievements of the 20th century [1]. Routine childhood immunizations are effective public health intervention, saving countless children worldwide from illness and death, promoting equality and equity in health, and allowing the realization of human potential [2].

Despite the benefits of vaccines, vaccinations have evoked resistance among parents who are personally opposed to immunizing their children as well as among organized groups that oppose vaccination as part of their political-social-economic agenda [3]. Under-immunization may reduce population immunity below the herd immunity threshold and can lead to outbreaks of vaccine-preventable diseases in various communities and among children who have not been immunized. In recent years, an increase in the incidence of vaccine-preventable diseases such as pertussis and measles has been reported in the USA, the UK and in other developed countries, as a result of a decrease in the vaccine coverage rates against these diseases [4-7]. Most of the studies analyzing the reasons for that trend have focused on parents' philosophical or ideological ideas that influence their decision to avoid immunizing their children, despite public health recommendations. Other reasons for not vaccinating children include medical contraindications, insufficient communication with the medical staff, lack of knowledge or erroneous knowledge among

parents about vaccine-preventable diseases, low availability of and access to medical services, and low trust in medical authorities [8-10]. Generally, the rate of unvaccinated children ranges from 1%-20%, depending on the study and its setting [10-12]. The reasoning behind parents' decision not to vaccinate or to only partially vaccinate their children is complex and multi-dimensional, and is often associated with libertarian autonomous ideologies [13] as part of the perceptions regarding control over life [14].

The Israel National Immunization Program (INIP), as outlined by the Ministry of Health (MOH), is designed to include all children from birth. The program includes vaccines against twelve diseases and is available free of charge for every child. The INIP is non-mandatory, and the decision to vaccinate is made voluntarily by parents, and yet more than 90% of Israeli children have received all recommended vaccines by age two [15]. Despite the high level of vaccine coverage, records indicate that there are specific groups of parents that do not fully vaccinate their children. Occasionally, there are outbreaks of vaccine preventable diseases, such as measles, mumps or pertussis and most of them occur among communities with low vaccine coverage [16].

The aim of the study was to identify the main reasons that some parents in the second largest urban city in Israel, opted to vaccinate their children in a manner that deviates from MOH recommendations.

## Materials and Methodology

### Research design and sample

A qualitative approach with a purposeful sampling was selected to describe and understand parents' narratives and world views regarding pediatric vaccinations. The case study methodology made it possible to conduct an in-depth investigation, focusing on a small number of informants whose explanatory narratives could shed light on the phenomenon under investigation [17].

Participants included in the study were parents of infants born in 2009 who did not follow the recommended course of routine vaccinations appropriate to their children's age. Participants were recruited from Mother Child Health Clinics (MCHCs) represent northern, southern and central areas of the city, as well as a wide range of vaccination options. The final sample size was determined when new respondents provided no new information, indicating that a point of saturation was reached [18].

### Data collection

Data were collected over a period of three months, beginning in January 2011, using face-to-face in-depth interviews based on a semi-structured questionnaire of 23 questions; Interviews lasted 30–60 minutes. The questions probed parents about their general views on vaccination, reasons for not fully vaccinating their children, their opinion of herd immunity and social norms, their trust in the official medical system's general recommendations, and their decision-making process regarding vaccinating their children.

All participants received oral and written information about the study and its aims, and signed an informed consent form. Participants were apprised of their right to withdraw at any time, and anonymity was promised.

### Data analysis

Interviews were audiotaped and then transcribed verbatim. All verbal and nonverbal elements were transcribed: laughs, hesitations in speech, mumbling, or interruptions (e.g. a telephone ringing). When voice intonation was significant to the context of the text, it was mentioned in the transcription, for example: "The mother's tone was dismissive".

Data were analyzed in three stages proposed: open coding, mapping analysis, and focused analysis [17]. In the open coding, each interview was organized in a table format, to enable the identification of main concepts, and each concept was given a code name that represented the central message. In the mapping analysis, these codes were compared and a total of 100 codes were organized in a chart, which was used to search for horizontal and vertical connections between codes that arrange themes and subthemes by priorities. In the focused analysis, codes or subthemes that were not significant to the main issue were removed. Finally, five horizontal themes were defined.

## Results

Fourteen parents were recruited, but two of the mothers opted out due to personal time constraints. Demographics data of participants and vaccination status are presented in table form (Table 1).

Name	Age	Profession	Family status	No. of children	Vaccination status	Area of living in TLV
I	32	Student second degree in alternative medicine	Marriage	2	IPV-4; DT-2; Hib-4	North-east TLV
y	33	Hi-Tec profession	Marriage	2	IPV-4; DT-2; Hib-4	North-east TLV
A	29	Academic nursing; not working	Marriage	2	No vaccination at all	Center TLV
V	37	Lawyer in environment quality	singled	2	DT-2	Center TLV
M	35	Confectioner; not working	Marriage	3	DTaP-3; IPV-3; Hib-3	North TLV
L	34	Interior decorator	Marriage	1	DTaP-3; IPV-3; Hib-3	South TLV
N	37	Psychologist	Marriage	1	DTaP-3; IPV-3; Hib-3	South TLV
R	30					
	Physio therapist	Marriage	1	DT-2; Hib-2; IPV-2;	North TLV	
Z	33	Alternative medicine; not working	Marriage	1	DT-2; IPV-2; Hepatitis B -2	North TLV
S	30	Economist; not working	Marriage	2	DTaP-3; IPV-3; Hib-3; Hepatitis B -3	East TLV
C	32	Academic nursing	Marriage	1	All vaccination completed except hepatitis A	South TLV
B	40	Secretary	Marriage	3	IPV-2; Hib-2	East TLV

**Table 1:** Subjects characteristics.

The interviewees' choices demonstrated a wide spectrum of vaccination programs for their children (Table 2): at one end of the spectrum was a mother refused the administration of any kind of vaccination, while at the other end of the spectrum was a mother who intended to have her daughter receive all of the required vaccinations, but slightly later than recommended. Between these two ends were parents who agreed to some of the recommended vaccinations,

depending on their world view: some asked for an alternative vaccination schedule, others asked to separate combined shots and administer each separately, and yet others agreed to have their children vaccinated, but asked that the first vaccination be administered only after the child was at least 12 months old, and that the process be staggered over a period of time longer than the norm.

Vaccine Variation	Vaccine Recommendation as	Vaccine not as	Absolutely Refuse	Number				
		Vaccine In The First Life	Vaccine After One Year Old (Second Tear)					
	Complete Vaccine	Complete Vaccine With Slightly Delay	Vaccinati-on only for "life-endangering" diseases	Divide vaccine combina-tion in interval of 5 years	Vaccine only "frighten" diseases, divide vaccine combinat-ion in interval of 5 years	Vaccine for only 3 diseases that "must" have vaccine against them		
No. of subjects	0	1	2	1	2	5	1	12

**Table 2:** Variation of vaccination.

### Parents demand an autonomous decision regarding their child's vaccinations

Most of the interviewees mentioned their demand for autonomy in making their own decisions about their body and health including vaccination administration. In their opinion, everyone should have the freedom to decide in this matter, and it is the parents' obligation and right to do as they see fit for their children. Choosing an alternative vaccination program, asking questions, and investigating the issue all represent their autonomy and freedom of choice, as L said:

I think that everyone has the right to choose his way of life, especially if it concerns his child, because if something happens to your child, you will have to deal with it alone, by yourself. Nobody else will. This is my child not the government's child.

As part of this self-chosen liberty, the parents want a personally tailored vaccine program that matches their lifestyle, their children's developmental stage, and the family's health background. They are not unilaterally opposed to all vaccinations, but they think that the national vaccination program represents a general decision of the MOH that encompasses all children with no personal tailoring or reference to specific children's needs, as I said:

We vaccinated our firstborn when he was one year old,... when he began to walk, when there was a possibility of injury. It's important for us that the vaccination schedule matches his personal development and is suited to our lifestyle.

### Making health a personal responsibility

For most of the interviewees, vaccination has become a symbol of taking individual responsibility of one's health. The parents argued that in a democratic country, where knowledge and information are freely accessible (especially through the Internet), where advanced laws ensure comprehensive medical insurance and patient rights, individuals have the obligation to take responsibility for their own lives, in health as well as in sickness. Therefore, people should no

longer believe blindly that whatever the doctor says is automatically the best option. Instead, people must be equal partners, actively involved in making health decisions, for better or for worse and taking responsibility for the consequences of their decision. Thus, refusing medical treatment or preventing procedures such as vaccinations is perceived as a positive action, and not as a negative act of rejecting the doctor's opinion, As Z said:

I think that the medicine took away our connection to our body. People have to understand what suits them. I think, as I see how doctors are acting and treating patients, every person has to take responsibility for his or her own health. People should examine their needs, to see what works for them individually... Today, everyone can read, everyone has access to information. Go ahead! Make your own decisions. Like you do with everything else in your life, you have to make your own health decisions too! All the more so when it comes to your children's health.

### The parents' comprehensive role: The "good parent"

It was very important for these parents to emphasize that vaccinating according to a different schedule did not indicate child neglect; quite the contrary, they were devoted and attentive parents, and were especially cautious about monitoring the development of a child's illness. Some mothers thought that preventing disease deprived them of the opportunity to be by their children in times of illness, which they interpreted as missing the opportunity to forge the mother-child bond. From this perspective, vaccinations are perceived as a negative factor, which impinges on a mother's sharp instinctive sense of her child's health and harms the mother-child bonding. As N explained:

Janusz Korczak, the famous pediatrician, wrote an amazing sentence in his book: "If a mother says that there is something wrong with her child, even if the doctor cannot see it, in most cases she knows better than her doctor". If you prevent the mother from constantly listening to her child because of a vaccine, antibiotics or other medical technologies, the mother can lose that instinctive sense.

Most of the participants argued that their approach demonstrated better parenting than that exhibited by compliant parents, given that they contributed more to their children's health and welfare. Parents reported that they searched for updated information and asked experts in the fields of conventional, alternative, and homeopathic medicine; consulted with laymen friends, and read up on arguments for and against vaccinating. Some said that they always asked "why" after receiving an answer and they felt pride and satisfaction when their questions about vaccinations raised doubts among conventional medical doctors and nurses. They felt that their knowledge empowered them, enabling them to talk with experts on a professional level, As R said:

I don't do things automatically; I check everything... I investigate approaches with all kinds of people, some who think like me and others who do not; I seek and give advice all the time and, yes, it makes me a better parent.

### **The factor of criticism and distrust of the medical establishment**

Eleven of the interviewees mentioned that the MOH does not publish all the information available about vaccines. In their opinion, external interests prevent full disclosure of information. Consequently, they don't trust the public health establishment. Four parents mentioned buying and reading anti-establishment and "underground" books through the Internet. The authors of these texts claimed that their ideas were so innovative and critical of official policies, that they could sell the books only on the Internet.

Notwithstanding, most parents expressed their complete trust in Israel's advanced healthcare system. They were absolutely certain that if their child fell ill with a childhood disease such as the mumps or rubella, the healthcare system would care for the child until full recovery. "After all", they said, "children in Israel do not die from infectious diseases".

### **Perception of Risks: Vaccine vs. Disease**

Most of the interviewees weighed the risk of contracting one of the preventable diseases, with its concomitant complications, against the inherent risk posed by the vaccination itself and decided against the vaccine. The majority of vaccine preventable diseases were perceived as trivial and simple, with no complications for the child. In their opinion, some diseases, like polio and diphtheria, seem to have disappeared, so the vaccines were unnecessary. Some of the parents thought that haemophilus influenzae type b or tetanus were serious diseases so they vaccinated their child against those, but only after the child was at least one year old. A few parents said that these diseases were found only in low socioeconomic communities (such as foreign workers or the radical ultra-Orthodox), not in their own communities. At the same time, most of the interviewees believed that vaccines can cause serious side effects that could impair the child for life. They believed that much more is unknown than known about vaccines and that the long-term side effects have not been revealed yet. The parents were worried about their own child's vulnerability to the vaccinations and not about the general side effects of the vaccines. When they compared the two risks, they considered the vaccination risk to be higher than the risk of contracting the disease, claiming that medical care cannot deal with rare and complex diseases like autism or autoimmune diseases, which can be caused by vaccines. M stated the following:

I vaccinated my eldest daughter with the MMR vaccine. After that, I sat at home worrying, crying all day: I did something wrong to my daughter, I made a bad decision; she was not acting normally because of it, and I destroyed her life; people say that MMR causes autism.

## **Discussion**

### **Obtaining control of life**

All of the parents interviewed expressed attitudes that emphasize their desire to control over health-related decisions. A number of studies found perception of control to be a predictive factor of health promoting behavior and its outcomes [19,20]. The initiative to monitor one's own healthcare indicates a willingness to assume responsibility based on an understanding of what health is, how to improve it, and how to treat deviations from it [21]. In this study, the parents believed in their ability to influence their children's health, through what they considered to be wise decisions. However, the actions of these parents contradict, rather than conform to the health institution's definition of health-promotion, as manifested in the vaccination recommendations prescribed by the MOH.

Research has shown that people who searched for information about the risks involved in an accepted medical intervention have been found to believe in their direct control over their health more than people who did not seek such information [22,23]. In this study, the parents who proactively sought information considered themselves capable of finding information, understanding medical matters, and making informed decisions. Thus, they exhibited a high sense of self-efficacy in this matter, which enabled them to deal with the potential consequences of their decision to defy standard recommendations for pediatric immunization. In other words, they felt confident enough not only to reject conventional wisdom, but also to follow their own conclusions. Furthermore, some of the parents felt their decision in this matter made them better parents. Such feelings are reinforced by parent anti-vaccination groups, which refer to their ability to deal with the various medical issues a "reward," and "proof" of responsible parenting. The parents' decision has long range implications for their children's lives, thus making the "right" vaccination decision a symbol of "good parenthood" [24].

### **Autonomy and liberalism**

Autonomy and liberalism are critical components for understanding parents' vaccination decisions. Recent social, political, and legal processes (e.g. the National Health Insurance Law, Patient's Rights Law, Internet sites and other sources) have encouraged greater patient autonomy in dealing with medical services. Underlying the autonomy model is the belief that patients can identify the most appropriate treatment decision for their children's well-being, even if that decision is a refusal to accept medical treatment [25]. In this study, the parents wanted the freedom to say "no" to the medical recommendation from a position of power, after considering the advantages and disadvantages as they analyzed the issue. Recent studies have highlighted the social implications of people's decisions about vaccinations and found that people are motivated by liberalism and individualism; hence, the communal benefits of vaccination are less important to them. The choices they make seem rational to them, given the information they have [13,26]. Beck and Giddens [27], called this decision-making process reflexive thinking, meaning that in modern life, people make their own decisions by independent thinking, regardless of what the "government says". They take the risk that they may be wrong, but they

make their own decisions. Regarding vaccination issues, Velan et al. [26] argued that most of the people want to be more active in the vaccine decision making, through judicious acceptance of the vaccine program and tailoring the vaccine programs to suit their preferences. They can differentiate between the varied vaccines and choose the vaccine that advances their family's best interest. Many people are not necessarily against vaccines, but they seek answers to questions about vaccine safety, schedules, changing policies, and the relevance of some vaccines. Some are concerned about their genetic susceptibilities to side effects of vaccines [28]. All these concerns are from the individual's point of view, disregarding the communal benefits of vaccination. Liberalism and reflexive thinking encourage criticizing massive vaccination programs and challenging the public health authorities [29]. The scientific answers are not always acceptable to consumers. An example is the concern that MMR vaccine causes autism, despite an abundance of scientific evidence that shows no causal effect [28]. Nonetheless, people want the freedom to decide which aspects of scientific evidence they accept and believe and which they reject.

Lay people analyze and understand medical information differently than do members of professional medical staffs [30]. People do not worry about the average risk from the vaccine; rather, they decide which risks are unacceptable to them, and perceive this decision as securing their autonomy and their control over their lives [24,30]. In this study, the parents felt that they could weigh which risks they could afford to take, for example, contracting measles, and those they could not, such as autism, which they presumed to be associated with the MMR vaccine. In most cases, the parents don't have all the scientific information about vaccines; in fact, they make a pseudo-rational decision based on homeopathic perspectives or Internet and media sources, some of which provide no scientific basis whatsoever [31].

This study has some limitations. It was a qualitative study with a purposeful sample, i.e., a small number of informants who are not representative of the entire population of Israel. Therefore, in order to be able to generalize from the findings, a follow-up quantitative study is necessary. Furthermore, the sample was chosen from a population of children registered at the MCHC in a large city and does not represent children whose parents were not registered at MCHCs in this city or who reside in other parts of Israel.

In addition, Israel is characterized by high accessibility to MCHC services, at no additional cost to the patient; despite this, the parents in the current study chose not to vaccinate their children or to partially vaccinate them. Therefore, it can be difficult to generalize from these findings to countries with less accessibility to healthcare.

## Conclusion

In modern society, it seems that people manage decisions pertaining to the social context through a reflexive process. They weigh the potential risks and benefits of the vaccinations and respond differently to each vaccine. Thus, they perceive themselves to be highly assertive, independent entities, competent to make autonomous decisions about vaccines. The parents in this study exhibited a wide range of attitudes and beliefs about vaccination. These findings indicate that an effort should be made by public health nurses to involve parents in vaccination decisions and to support their personal responsibility and control for their children's health, while providing accurate, evidence-based information. Expert public health nurses need to recognize the ability of the lay public and of parents in particular to understand and

take responsibility for their own and their children's well-being. It is the professional's obligation to tailor the intervention to suit the needs of these parents and address their concerns, in order to ensure high vaccination coverage.

## Conflicts of Interest

The authors confirm that they have no conflict of interest in regard to this manuscript.

## Ethical Approval

The study was approved by the Ethical Committee of Human Experimentation, Faculty of Social Welfare and Health Sciences, University of Haifa, Israel.

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