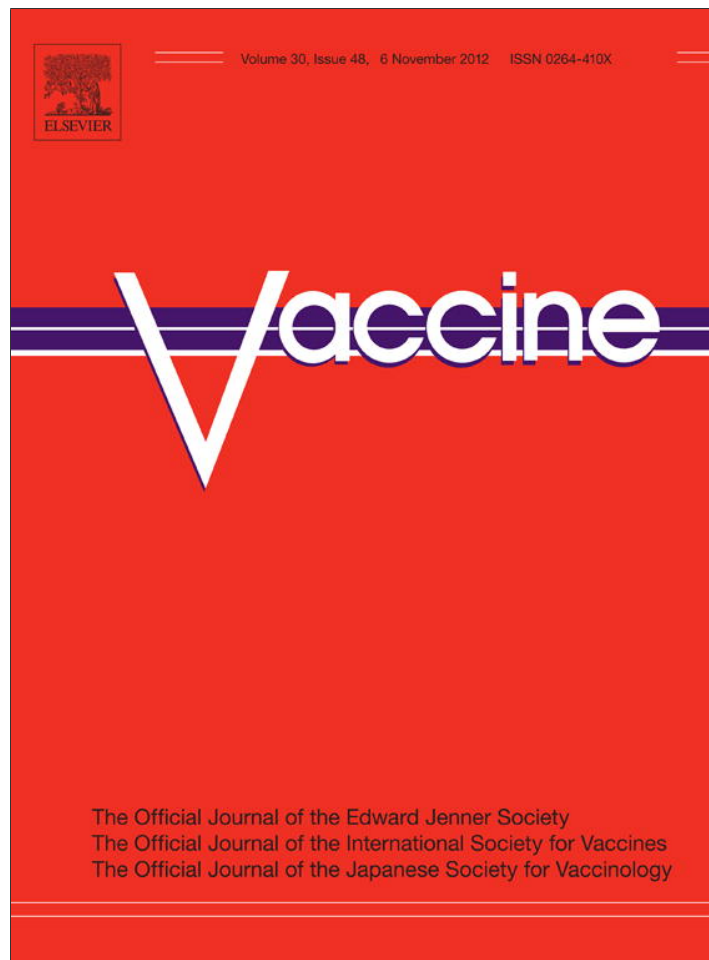


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“Who will take the blame?”: Understanding the reasons why Romanian mothers decline HPV vaccination for their daughters

Catrinel Craciun*, Adriana Baban

Babes-Bolyai University, Cluj Napoca, Romania

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ABSTRACT

Because Romania has the highest incidence of cervical cancer in Europe, in 2008 a HPV vaccination campaign was introduced targeting 10–11 year old girls. However, only 2.5% of the eligible girls were given parental for vaccination. Campaign failure makes it important to look for possible reasons and investigate mothers' attitudes and perceptions of the HPV vaccine. Three focus groups and 11 interviews were conducted with mothers from urban areas. Data were transcribed verbatim and analysed with thematic analysis.

Results show as main reasons for not vaccinating their daughters perceiving the vaccine as risky, the belief that the vaccine represents an experiment that uses their daughters as guinea pigs, the belief that the vaccine embodies a conspiracy theory that aims to reduce the world's population and general mistrust in the ineffective health system. Mothers stated they would need clear, factual information about the HPV vaccine and its link to cervical cancer in order to motivate them to accept it for their daughters.

The study offers insight into the beliefs and attitudes towards the vaccine and provides ideas for structuring future health communication campaigns regarding the HPV vaccine.

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1. Introduction

Nowadays, the sexually transmitted infection with Human papillomavirus (HPV) has become one of the most frequent worldwide [1]. Romania has the highest rate of cervical cancer mortality in Europe [2], owing to a lack of national systematic screening programmes, poor opportunistic screening attendance and the deterioration of the medical system [3,4]. Types 16 and 18 of the HPV were shown to be involved in 70% of cervical cancer cases globally [5].

Following the recognition of HPV as a factor in determining cervical cancer, a new paradigm of prevention emerged focusing on HPV immunisation in addition to cervical screening [6]. A prophylactic HPV vaccine was introduced for protection against infection with types 16 and 18, with high potential for reducing the burden of disease [7]. Since 2006, the anti HPV vaccine is recommended for girls and women in the 9–26 age group [8].

Because of the vaccine novelty, many people are sceptical about its effectiveness. For instance, during the vaccination campaigns in 2008 in the USA, less than one quarter of teenager girls were vaccinated [1]. Numerous studies have been undertaken to identify the factors that determine vaccine uptake. Previous research shows that parents play an important role in shaping childrens'

and teenagers' attitudes towards vaccines [9]. For instance parental attitudes influenced teenagers in what concerns Hepatitis B vaccination [10].

Since mothers are the ones who mostly make health decisions for the family including vaccinations [11], their attitudes and beliefs about the HPV vaccine are considered crucial for the success of vaccination campaigns. Research on mother's main reasons for rejecting the vaccine showed lack of knowledge about HPV, age-related concerns (i.e. their daughters are too young to be vaccinated), low perceived risk of infection, concerns about vaccine safety, long-term side effects, responsibility for the vaccine's consequences [12] and risk compensation after the vaccine, namely an increase in their daughters risky sexual behaviour [13] to play a major role in their decision. Reasons for accepting the vaccine included: the desire to prevent illness, high perceived risk of infection [7,14], approval from partner and other mothers or having someone in the family with cancer [15].

In 2008 the Romanian Ministry of Health launched the HPV vaccination campaign. Girls aged 10–11 could be vaccinated free of charge after receiving parental consent. The vaccination campaign was run mainly in schools, but the vaccine was also available from general practitioners (GP). School doctors and GPs were trained to inform parents about the vaccine. Initially, in 2008 parents had to approve or reject the vaccination in writing (opt-in). Later, after the programme was re-launched, in 2009, the Minister of Health decided that written parental consent was no longer necessary (opt-out). Parents could approve or decline the vaccine verbally.

* Corresponding author. Tel.: +40 740150966.

E-mail address: catrinelcraciun@yahoo.com (C. Craciun).

Table 1
Participant information.

City	Total N	Age range	Range of number of children	Range of ages of children	Types of professions
Cluj-Napoca	16	30–50	1–2	2–29 years	Economist, historian, secretary, psychologist, teacher; housekeeper, unemployed, cook, shopkeeper, cleaner (housemaid), public servant
Cluj-Napoca	9	30–45	1–6	1–17 years	

Statistics from 2008 revealed that only 2.5% of the 110,000 eligible girls in the target group were vaccinated [16]. Thus, a re-launching of the vaccination campaign was planned for 2009–2010, targeting girls between 12 and 14 years old. There is still no national standard recommendation about the vaccination and currently the campaign has stopped due to low uptake and the fact the many vaccine doses have expired.

The present study set out to explore the experience of Romanian mothers with the HPV vaccine. In addition to identifying their perceptions and attitudes towards the HPV vaccine, we also wished to understand their reasons for accepting or rejecting HPV vaccination for their daughters. Moreover, we aimed to comprehend what kind of health communication would mothers need regarding the HPV vaccination (i.e. what kind of information, who should deliver it, etc.).

2. Method

The present data are part of a larger international project on “Psychosocial, Political and Gendered Dimensions of Preventive Technologies in Bulgaria and Romania: HPV Vaccine Implementation”, carried out in 2010–2012. The research project aims to tackle personal and social meanings of the HPV vaccine in the two countries, by analysing media discourses and parental, doctors and policy makers perspective on this preventive technology. The focus group and semi-structured interview guide comprised questions on attitudes towards the vaccine, intentions, knowledge and behaviour (see Table 1).

Three focus groups and 9 semi-structured interviews were conducted with Romanian women, aged 30–50 (see Table 2), and mothers of girls in the vaccine target group from Cluj Napoca.

Ethical standards were respected in what concerned data gathering, transcriptions, analysis and reporting. Participants signed a consent form upon agreeing to take part in the project and received the equivalent of 10 US dollars for their participation. Criteria for inclusion were: having a daughter in the vaccination target group and having been in the situation to make a decision vaccination.

Table 2
Interview guidelines.

Introductions (participants in FGs can use pseudonyms if they like) and information about the study.
Where would you go if you needed to find some health information?
What about if you needed information specifically for the prevention of cervical cancer?
What is your opinion about the recently introduced vaccine for the prevention of the HPV virus (and the prevention of cervical cancer)? (Probes: is it a good thing to have the vaccine, is there anything about it that bothers you?)
Where are you hearing information about the vaccine?
What would you say about the information you are receiving about the vaccine?
Currently, the vaccine is given to young girls and older women who do not have HPV.
What will influence your decision about whether you yourself will get vaccinated?
What will influence your decision about whether to have your daughter vaccinated?
What will influence your decision about whether to have your son vaccinated?
Is there anything else that you think is important for us to discuss about the HPV vaccine?

Recruiting was done through local advertising and schools. Focus groups lasted on average 1 h and 30 min and interviews around 40 min. These were conducted at the Institute of Psychology. Participants did not know each other. Interviews were done and transcribed verbatim in Romanian. Relevant quotes were translated into English for publication purposes.

The analysis was informed by the social constructivist perspective [17], acknowledging that both the perspectives of the interviewer and the participant shape how we understand the studied phenomenon. Emerging themes were initially coded and then broader categories were formed. Thematic analysis was applied, following the steps described by Brown and Clarke [18]. All themes were checked by the two authors.

3. Results

3.1. The risky vaccine

Mothers feared the vaccine and were concerned about the negative consequences it could have on their daughters' health. Fear of future infertility and severity of such a problem were highlighted by several participants, as infertility means “*you are not a woman anymore*” (focus group 1). This possible side effect of the vaccine is perceived as being far more severe than developing cancer if not vaccinated. The vaccine came out as less relevant for health and acceptance would mean “*I would destroy her femininity ...*” (focus group 2). Positive consequences of the vaccine were underplayed as these are perceived as uncertain and not worth taking the risk. Some participants believe that the vaccine makes you susceptible to getting cancer in the future.

3.2. Who will take the responsibility for the possible negative effects?

The idea of responsibility determines mothers to evaluate risk differently for themselves compared to their daughters. Participants said they would accept the vaccine for themselves, but for their children they “*cannot take the risk*” (focus group 3). They argued “*that they themselves are not important*” (focus group 1), but children have “*a whole future ahead of them, they have to give birth to the next generations*” (focus group 1). As mothers, they felt responsible for their children's health and take on a protective role. One negative example is enough to make them decide to reject the vaccine. Some mothers mentioned their daughters are “*too young*” for the vaccine (focus group 3). When they are older they can decide for themselves. Participants believed boys should also be vaccinated because responsibility for sexually transmitted infections has to be shared by both genders.

3.3. Conspiracy theory

The idea of infertility as a possible side effect seems to emerge from information posted on the Internet. Apparently, some internet forums present a **conspiracy theory** which argues that the vaccine represents a strategy to reduce the world population. This, combined with the vaccine being offered free of charge, has made women suspicious. The gratuity of the vaccine meant uncertain vaccine results and hidden medical interests. It was presented as a problem embedded in the socio-economic and cultural Romanian

context: . . . in the present Romania it is not good either way. If somebody offers you something for free, you are sceptical. You ask yourself why? when you have to pay, you ask yourself why so expensive? But when you pay, you have the feeling you pay a good service. (A, 35 years old, school teacher).

3.4. Vaccine as experiment

The vaccine was represented as an experiment serving the commercial interest of pharmaceutical companies. Mothers mistrusted the pharmaceutical industry who would “do and say anything in order to sell their products” (B, 45 years old, economist). These will be the “winners” of the campaign and will make “huge profit” from selling the vaccine after testing it on their daughters (focus group 1). The vaccination campaign was understood by some women as **an experiment** and anger was expressed concerning their children being “guinea pigs” to serve commercial interests.

Another reason to believe the vaccine to be an experiment is that it is conducted in Eastern Europe. Mothers felt victimised in comparison to more developed regions and thought other countries have refused the vaccine because it is not good. They were concerned that Romania accepted to conduct the campaign and complained that Romanians will be “a victim” in this “experiment” (C, 42 years old, public servant). Being asked for vaccination consent was also seen by parents as proof for the vaccine being an experiment. Parental consent represents a novelty, since parents were used with compulsory vaccination campaigns. Being given the possibility to choose, they felt responsible and doubtful of vaccination purposes.

3.5. The vaccination campaign as the reflection on an ineffective health care system

Mothers complained about the ineffective Romanian health care system and the **lack of information** provided. Most did not understand how the vaccine works and how it is linked to cervical cancer prevention. They distrusted doctors because these seemed unconvinced about the positive effects of the vaccine, lacked objectivity and represented commercial interests. Some doctors who advertised the vaccine in schools were perceived as being “a bit too enthusiastic” and “insincere” (D, 45 years old, housewife). One participant said she had asked her doctor if she would vaccinate her own daughter and the doctor answered she would not. Such contradictory messages, on the one hand promoting the vaccine and on the other hand criticising it, generated confusion and mistrust.

The vaccination campaign was perceived as a failure due to its faulty organisation and attitude. Mothers felt the vaccine was “pushed” on them without providing proper information. Some participants felt offended by this procedure. The main theme was **lack of respect** for the target audience. Some mothers perceived it as an offence, “as if we were some kind of animals” (E, 40 years old, shopkeeper), because they felt they were expected to accept the vaccine without being informed. The campaign ineffectively assumed “free” is a magical word and will convince mothers to vaccinate their daughters. Gratuity could not compensate for lack of information. Some mothers even took pride in not accepting the “free vaccine” since rejecting the vaccine proves they respect themselves and their daughters. Participants referred to the vaccination campaign as being “typical of how the Romanian system works” (focus group 2). Thus, lack of planning and proper evaluation seem to be cultural characteristics, described as a “Romanian defect” that also influence how the campaign was conducted.

3.6. How to communicate about the vaccine?

Participants expressed their desire to be thoroughly informed about the vaccine, its consequences and link to cervical cancer. The school environment would not be ideal to inform the parents as they mentioned they often do not go to school due to lack of time. However, they emphasised they would like to take part in information sessions. Parents of teenagers emphasised that separate information sessions should be organised for the adolescents themselves in addition to parents being informed.

The influence of “other mothers” is regarded as very important. If other mothers say they accepted the vaccine, this would reflect positively on the vaccine, while it takes only some mothers who decline vaccination in order that also other mothers refuse to do it. Before deciding, one asks to see what other parents have decided. This is invested with a special kind of authority that “only mothers would understand” (focus group 1).

For educated women, the main source of information was the Internet while for less educated ones, the doctor represented the authority for medical information. Most participants believed communication about the vaccine needs to be clear and simple. Otherwise, especially people with a low education level will remain uninformed and unmotivated since they will not take initiative to inform themselves. This is why participants felt the campaign should be conducted over a longer period of time. Changing cognitions takes time and reducing mistrust in the health system is a long process.

Doctors were regarded as an important source of information only if considered trustworthy. Trust criteria were very different: the expertise, the amount of time that one knows the doctor for instance if he/she has been their doctor for a long time (i.e. since the birth of the child). If the doctor is trusted in general, than his/her recommendation of the vaccine will play an important role in the vaccination decision.

Women enjoyed the fact that the vaccine is not obligatory and they liked that they were asked for consent. They wanted more information to make an informed decision. Otherwise they do not want to take the risk of being responsible for the side effects that the vaccine could have on their daughters. However, some of the interviewed mothers considered that doctors should primarily take responsibility for the children's health, and consequently, for the effects of the vaccine.

4. Discussion

One of the main themes that emerged from the interviews was **the HPV vaccine as risky**. Findings show that risk perception concerning the unknown side effects of the HPV vaccine outweigh cancer risk perception. Compared to previous studies [19,20], mothers perceive their daughters to be less susceptible to developing cervical cancer, while they strongly believe the vaccine can cause infertility. Previous research has shown low perceived risk of infection as determining vaccination rejection [8]. However, Romanian mothers are more concerned about **taking the blame** for the vaccine's long-term side-effects than risk perception. Compared to US parents, who fear the compensatory effects of the vaccine on the teenager's engagement in sexual risky behaviour [12,14], Romanian parents mostly fear the vaccine will determine their daughter's infertility. Different from previous research, infertility is seen as much worse than the risk of getting cancer, since it “destroys your femininity” and “makes you not be a woman anymore”.

Risk perception is linked with feelings of blame and anticipated regret about the possible negative effects. Drawing on the message framing theory, loss-framed messages should be more effective in the case of HPV vaccine promotion as compared to

gain-framed ones [21]. Also, studies showed anticipated regret plays a more important role than risk perception [22]. Thus, in order to compensate for the existing negative information regarding vaccine acceptance, loss-framed messages about the negative consequences of vaccine decline should be designed. Messages of anticipated regret combined with messages about the effectiveness of the vaccine could be more persuasive, adding to recommendations from existing literature [21]. Starting from the present results, in the Romanian context, loss-framed messages highlighting anticipated regret may be most effective.

Parents emphasised their fear and worries regarding the risky HPV vaccine, showing that their decision relied on emotional strategies. This lends support to previous research that argues that when people have to make decisions which they consider risky under conditions of uncertainty, these can be explained by affect heuristics [23]. When mental resources are limited, people tend to make decisions based on affective impressions [24]. This must have been the case for Romanian mothers as they describe the campaign as ineffective because they were given unclear information. Thus, they refused vaccination based on their negative emotions towards the risky vaccine. The prevalence of negative affect could be explained through the high number of negative information about the vaccine present in the Romanian media. The main concerns were side-effects and insufficient testing [25], ideas reflected in the mother's discourse about the vaccine. When faced with uncertainty and lack of information, participants tended to perceive possible negative side-effects as certain, while treating possible positive effects as highly improbable.

All in all, mothers agree the vaccine should not be obligatory and are happy to be asked for consent. However, compared to other studies [12,19] they do not want to take responsibility for the vaccine. They want the doctor to tell them if the vaccine is good or bad, to provide advice and take on the decision responsibility. This is perceived as difficult as many doctors are considered unreliable and not being objective due to material interests and thus irrelevant for the decision process. In this context, the **vaccine is seen as an experiment** of the pharmaceutical industry and the reflection of a **conspiracy theory** that portrays the vaccine as an attempt to reduce the world's population. Another related theme is that of **campaign failure that reflects the ineffectiveness of the Romanian health care system**. Mothers complain that the campaign provided contradictory information and lacked respect towards the target audience. A novel point is that lack of trust in the medical system translates into mistrust regarding the vaccine effectiveness. People are disappointed by doctors and the medical system, and the vaccine becomes a symbol for how things work in Romanian health care and how patients are treated. This information has to be understood within the cultural and historical context where up till now, parents were not given the opportunity to decide about their children's health. Vaccines and medical check-ups were compulsory. Thus, parents did not need to reflect on such issues and lack the practice of being informed patients. All the more, they highlight the need to be informed in future vaccination campaigns.

As women say, attitudes need time to change. This is in accordance to studies from the USA where women said that the vaccine should be on the market at least three years and solid studies should be available before they could consider vaccinating their daughters [19]. Social norms proved also very important in this context. In conformity with previous studies, what other mothers do and recommend is relevant for vaccination decisions [20]. Health communication campaigns could use mothers as role models to promote the vaccine. If doctors should recommend the vaccine, they should be empathic about parental information needs and provide clear and factual information [12] and address myths about the vaccine such as it causing cancer or infertility.

Thus, future information campaigns in schools should involve parents in a more active manner and use parental testimonies about the positive aspects of the vaccine, as well as anticipated regret about not having the vaccine. The benefits of getting to choose and making informed health choices should also be emphasised since this represents a novelty for the Romanian health care context.

Some limitations of the present study should be acknowledged. Results showed that all women who took part in the study had declined vaccination. Thus, especially in the focus groups, this could have influenced their attitudes and vaccine perception. Further studies should include both parents who accepted and who declined the vaccine in order to have a more balanced perspective. Moreover, mostly women agreed to participate in the study. Although mothers are the main health carers in the family, it would be interesting to investigate both mothers' and fathers' role and perceptions in the HPV vaccination decision process.

5. Conclusion

All in all, the present study offers insight into why Romanian mothers rejected the HPV vaccine for their daughters shedding light on vaccination failure in a previously unexplored context where people are not used to acting as informed patients. Results build on previous literature and show that risk perception is connected with anticipated regret and a focus on negative information. Moreover, it proves the use of emotional decision strategies when faced with uncertainty. It also supplements previous research by showing that mothers are perceived as better information sources than doctors when trust in health care is low. The study informs on how to structure the communication within future vaccination campaigns (i.e. use of loss-framed messages with anticipated regret, use of mothers as role models, etc.) in order to make them more effective and ultimately, to reduce the high mortality rates due to cervical cancer among Romanian women.

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