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THE VIEWS OF YOUNG WOMEN ON HPV VACCINE COMMUNICATION IN FOUR
EUROPEAN COUNTRIES.

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Abstract

The Human Papilloma Virus (HPV) is the most common sexually transmitted infection (STI) and can cause cervical cancer. Two vaccines are available to protect against the most common strands of the virus. Vaccination programs differ across Europe but most neglect young adults, who are the group with the highest risk of contracting STIs. Our aim was to explore the views of young women about the HPV vaccine communication strategy from four European countries—Scotland, Spain, Serbia, and Bulgaria. These countries are characterized by different cervical cancer prevalence and vaccine implementation policies. We conducted focus group discussions with young women (aged 18-26) with various vaccination histories in a purposive sample. We subjected the data to thematic analysis with the purpose of identifying themes related to communication about the HPV vaccine. We recorded the information sources mentioned by participants. Participants discussed numerous sources of vaccine-related information. They approached information critically rather than naively and questioned the sources' trustworthiness and motives. Participants desired transparent information about the risks of the virus and the risks and benefits of the vaccine. These risks and benefits were individualized in view of personal and external factors. Particular aspects of the vaccine and the way information was communicated resulted in feelings of uncertainty. There were notable cross-cultural differences in experiences with HPV vaccine communication. Our results suggest that transparent risk communication about the HPV vaccine is valued by young women. In addition, both individual and culturally-dependent factors influenced experiences with, and preference for, information.

Keywords: cross-cultural, Human Papilloma Virus, qualitative, risk communication, sexually-transmitted disease, sexually-transmitted infection, vaccination

THE VIEWS OF YOUNG WOMEN ON HPV VACCINE COMMUNICATION IN FOUR EUROPEAN COUNTRIES.

Effective risk communication is fundamental to improve health behavior in general [1, 2] and to prevent sexually transmitted infections (STIs) in particular. The Human Papillomavirus (HPV) is the most common STI and may cause a number of serious health conditions, including genital warts and cervical cancer [3]. Cervical cancer is among the most prevalent cancer types in women worldwide. In 2005, almost 260.000 women were estimated to have died of cervical cancer with 80% of the cases occurring in the developing world [4]. Since 2006, two brands of the HPV vaccine have been introduced to guard against those HPV strains responsible for 70% of cervical cancer cases [5]. The HPV vaccine is effective in preventing HPV infection and HPV related diseases in 90%–100% of cases [6]. It is well tolerated with mild side effects, which makes it one of the most efficacious vaccines available [7].

The HPV vaccine is increasingly available in a number of countries across the world [8]. In Europe it has been introduced with different implementation policies ranging from school-based mass immunization programs to on-demand delivery or private sector provision only. This has led to different uptake rates. For example, a school-based program in Scotland resulted in 92% coverage, while free on-demand provision in Greece in only 9% coverage [5]. Overall most countries in North-Western and Central Europe have implemented some sort of organized vaccination program or campaign [7]. In contrast, vaccination efforts in some South-Eastern European countries are still developing despite the region's higher burden of cervical cancer [9, 10]. Generally, programs have focused on vaccinating preadolescent girls before the onset of

sexual activity. Although a few countries offer catch-up programs for women in their twenties, this age group has mostly been neglected by vaccine policies [7], possibly due to cost-effectiveness [11]. However, vaccination of young women is generally recommended as young women can still benefit from the vaccine, even if they have been infected with HPV. Although HPV vaccination has no therapeutic efficacy in women who have already been infected, infection with one virus type does not impede vaccine-induced protection from another type [12]. Few countries offer catch-up programs for women in their twenties, and even fewer provide full insurance coverage [7]. Most significantly, women in their twenties show the highest HPV infection prevalence, which makes vaccination particularly beneficial [13].

Besides organized vaccination efforts, public communication is essential for informed decision making. The introduction of a new vaccine is accompanied by the challenge of educating the target audience with clear information [14]. Next to implementation policies, communication source, content, and form of the information shapes beliefs and behavior related to the HPV vaccine [see also 15-17, 2]. Concerns about risks and side effects can decrease intentions to get vaccinated [18, 19]. Even though the vaccine is not reported to have severe side effects, concerns about its risks may potentially be fuelled by negative reports in the media [20]. Anti-vaccine activism on the Internet and social media that advances the view that pharmaceutical companies exert undue influence for their own benefit can further increase skepticism [21].

Uncertainties are also increased by what is perceived by users as a lack of transparency in communication. Transparent communication may require complete, non-misleading, and factual information about the HPV vaccine and its associated risks in public media [22, 23]. A recent

analysis shows that health provider's materials may require more accurate, complete, and consistent information [24]. Some information might intentionally be left out, as it is potentially controversial to talk about young girls' sexuality [25]. A Canadian study, for example, found that around 20% of mothers assumed that HPV vaccination promoted promiscuity and were therefore less likely to get their daughters vaccinated [26]. This concern can be further fuelled by media coverage on the topic [27]. Even though this issue is expected to be less severe in more liberal societies (e.g., Denmark, [28]), health providers might still neglect the sexual nature of the transmission in the promotion of the vaccine [25]. Generally, there appears to be a need for improved information which includes not only transparent risk and benefit statistics [19] but which also addresses the socio-cultural aspects that might influence vaccination decision making.

Scientific reasoning alone might not be sufficient to deal with anti-vaccination attitudes [21]. The success of health efforts like the HPV vaccine introduction may be influenced by a country's unique history and culture and their implications for people's trust in health care systems, physicians and pharmaceutical companies (e.g., [29, 30]). For example, physicians' recommendations increased HPV vaccination rates among 19–26 years old women in Australia [31]. However, physicians' recommendations might not be taken into account if there is mistrust towards physicians and the domestic health care system such as in Hungary [32].

More understanding is needed of contextual aspects including historical experiences, religious or political affiliation, and socioeconomic status that play a central role in shaping public trust in vaccines [33]. It has become clear that a "one-size-fits-all-approach" to introduce a HPV program is problematic [21]. For example, the most prominent constructs used in health behavior models might not be universal and social context and cultural factors can influence health-

protective behavior directly [34]. Hence, an approach which focuses exclusively on individual level factors like those of most health-behavior models (e.g., Health-Belief Model [34], Theory of Planned Behavior [36]), can be insufficient to understand vaccination behavior in general and experience with information in particular. Qualitative research approaches can help in addressing this issue. They allow a thorough analysis and exploration of health issues and are valuable because they can take into account individual views embedded in social and cultural surroundings [37]. The differences in the implementation strategies of the vaccine across Europe offers a rich environment to investigate the reception of risk communication and the influence of policy and culture on individual decision making.

Aim

The aim of this paper is to explore young women's experiences with risk information about HPV and the HPV vaccine. We explored how women evaluated the quantity and quality of HPV-related information and information sources they consulted, and how this information affected their decisions about the HPV vaccine.¹ We focused on young women between the ages of 18 and 26 in four European countries: Scotland, Spain, Serbia, and Bulgaria. We chose this age group because women aged 18-26 are at high risk of contracting STIs and can benefit from vaccination. However, most HPV vaccination policies and campaigns target younger girls, thereby excluding this vulnerable age group. We chose these countries because they have

¹ A different analysis of the discussions related to broader policy and cultural issues covering knowledge, experiences with vaccination, and psychological and social implications of vaccination has been published elsewhere [38].

different implementation policies, thereby offering a variety of information exposure and experiences with HPV information.

Methods

We chose qualitative methodology in order to provide a rich description of women's experiences as embedded in their social, cultural, and personal context. We conducted focus group discussions with university educated women in Scotland, Spain, Serbia, and Bulgaria. These countries are characterized by different HPV vaccination strategies targeting adolescent girls. In particular, Scotland employs a national mass school-based program, Spain² offers free on-demand provision, while Serbia and Bulgaria offered only private provision at the time of data collection [5, 9]. None of the countries had implemented a catch-up vaccination program or any opportunity for vaccine cost reimbursement for women aged 18-26 [7, 9]. As a reimbursement for participation, participants entered a raffle with a maximum prize of 30 GBP in Scotland, 30 EUR in Spain, 3000 RSD in Serbia, and 50 BGN in Bulgaria, respectively. Ethics approval was obtained from the Research Ethics and Governance Committee at the leading institution Edinburgh Napier University, as well as the respective institutions at the University of Granada, the Serbian Psychological Society, and Sofia University.

Participants

Participants were women between 18 and 26 years old. They were recruited through purposive and snowballing sampling via posters, e-mailing lists, and forums in the local universities. We attempted to include women with various experiences and vaccination histories,

² In Spain, delivery of the vaccine varies by region [7]. Data collection took place in Granada, Andalucia, which offers free on-demand provision.

ranging from being vaccinated in school in the past to never having heard of the HPV vaccine before. We conducted eleven focus group discussions with 54 young women in total. Table 1 describes the demographic characteristics of the participants and their allocation among focus groups. All participants were university students, representing a mix of majors.

Table 1. Participant demographic characteristics

	Scotland	Spain	Bulgaria	Serbia	Total
Number of focus groups	3	3	3	2	11
Number of participants	10	25	10	9	54
Mean age	22.2	19.8	22.3	22.8	21.8
Sexually active	9	19	10	8	46
Vaccinated	4	3	0	0	7
Had prior knowledge about HPV vaccine	10	21	9	3	43
Attitude towards the HPV vaccine					
Interested	1	8	1	2	12
Unsure	6	8	7	7	28
Not interested	3	9	2	0	14

Data collection

The discussions were conducted between December 2011 and July 2012. The same procedure was followed in all four countries. All materials were translated into the local language. Participants were informed about the nature of the focus group discussion, signed an informed consent, and filled in an anonymous questionnaire with demographic information, sexual and vaccination history. All discussions lasted around one hour and were facilitated by two native speakers according to the same topic guide. The topics covered included participants'

opinions and experiences with vaccination in general and the HPV virus and vaccine in particular, including sources of information about the HPV vaccine. Towards the end of the discussions participants were presented with a sample of publicly available brochures about the HPV vaccine. These always included a brochure from the respective country in the local language. Additionally, brochures from the participating countries as well as other European countries were available. As the latter were in a foreign language, they were provided simply for visual inspection. The purpose of presenting the brochures was to provide a further basis for discussion. Participants were given time to get acquainted with the materials and had the opportunity to comment.

Analysis

The discussions were digitally recorded and transcribed by native speakers of the local language. Personally identifying information was removed. The Spanish, Serbian and Bulgarian transcripts were translated into English by native speakers who were fluent in English. To ensure quality of the translation random subset back-translations were performed [39].

Thematic analysis. The transcripts were subjected to thematic analysis following Braun and Clarke [39]. Thematic analysis is a method for identifying, analysing, and reporting recurring patterns (i.e., themes) within data. We adopted a mixture of inductive and theoretical approaches to our thematic analysis. In particular, we coded the data specifically for issues related to risk communication (as opposed to all interesting issues that might be present). However, we chose no particular theory or model against which to evaluate the data but preferred an exploratory approach. The topics we coded for included but were not limited to the following: (1) perceived risk of HPV and cervical cancer, (2) experience with, and perceived

quality, of risk information, (3) preferred information sources, (4) experience with, and perceived quality, of information sources, and (5) preferred/recommended manner of risk communication. We followed the steps outlined by Braun and Clarke [40] while taking into account the cross-cultural nature of our data. In particular, each coder (authors DP, AL, and RM) first familiarized herself with the data after receiving training in qualitative research. Then each transcript was coded for significant features by two coders. These initial codes were then organized into initial themes by each individual coder. Next, each coder was assigned a country for which she compared, summarized, and organized the initial themes into a thematic map first for each focus group separately and then for the respective country as a whole. The similarities and differences between the country's thematic maps were organized into an overall thematic map for the whole data set following extensive discussion between all coders. The final thematic map was refined by the first author after "going back to the data" to check if the final themes fit in relation to the coded abstracts (e.g., identifying telling quotes to illustrate the themes).

Information sources analysis. Participants discussed numerous sources of HPV-related information. Hence, we decided to subject our qualitative data to quantitative analysis (e.g., see [41]) in order to give a more thorough overview of women's experiences. We recorded the frequency with which participants mentioned 1) a unique information source from which they *obtained information* about the HPV vaccine³, and 2) a unique information source they *would consult* if they required such information. We grouped the sources into meaningful categories and computed the number of times a source from each category was mentioned in each discussion.

³ No differentiation was made between instances in which the participant herself searched for information from a source or was approached by the information source as this was not specified on many occasions.

Results

Thematic analysis

We identified two main themes: **Critical Appraisal of Information** and **Risk Adjustment** (Table 2). **Critical Appraisal of Information** encompassed two stages of obtaining HPV-related knowledge. The first stage of information reception was more passive: it reflected participants' appraisals of the available information. Common subthemes were *perceived lack of information* and *role of the media*. The subtheme *transparency* marked the transition to a more active stage of knowledge acquisition: Participants evaluated the transparency of the communicated evidence and purposefully searched for what, in their perspective, was transparent and trustworthy information. Other common subthemes were *active information search* and *information sources and reliability*. The theme **Risk Adjustment** reflected the stage of decision making about the HPV vaccine. The subtheme *my risk, my benefits* captured how participants perceived and adjusted their risk of HPV and the benefit of the vaccine in view of a number of personal factors. Other subthemes were *alternatives to vaccination* and *uncertainty*, which reflected how risks and benefits regarding HPV and the vaccine were interpreted in view of contextual factors. These themes were common across the four countries. However, some of the themes were more prominent in certain countries than others. Below we clarify the themes in more detail and provide excerpts from the focus group discussions to illustrate the participants' perspectives.

Table 2. Thematic framework developed from the analysis.

Critical	Lack of information
	Role of the media
Appraisal	Transparency
	Active search for information
	Information sources and reliability
Risk	My risk, my benefit
Adjustment	Alternatives to vaccination
	Uncertainty

Critical Appraisal of Information

This theme illustrates participants’ overall critical approach towards the information they encountered. Most young women in this study felt insufficiently informed and desired transparent information about the risks and benefits of the virus and the vaccine. When assessing the credibility of information, they questioned the trustworthiness and motives of information providers. Sometimes this led them to feel supported, and sometimes misled or manipulated.

We don’t know: Lack of information. Participants’ knowledge about HPV ranged from little to more advanced knowledge. However, a common perception was that the obtained information was insufficient to make an informed decision about vaccination. This idea was shared both by participants who took part in a school vaccination campaign and participants who had barely heard of the HPV vaccine. Further, this perceived lack of information often translated into an inference that the vaccine was not very important. Some participants thought that if the

vaccine was indeed beneficial, then more information would have been distributed, reflecting the support of authorities for the vaccine.

“And if the vaccine is still so important to cervical cancer, why aren’t they still giving information about it, so that more girls can get the jab? It was a craze that has stalled now.”

(P5, FG2, Spain)⁴

“Well, for me the primary reason is that, in reality, if the government wanted to support this thing, it would have provided more information, as a first step towards action.” (P1, FG1, Bulgaria)

Young women presented themselves as part of an information generation with access to knowledge sources. Yet, this privilege stood in contrast to their lack of knowledge about HPV. This is illustrated by a participant from Serbia who reflected on the far greater information disadvantages experienced by people with fewer educational and socio-economic opportunities:

“Well you [have us here] who are relatively educated and informed, who are following all sorts of things and then if we do not know ... Then I cannot imagine someone who does not have access to the internet and no access to television, how can someone know? But that's what we have here...” (P4, FG2, Serbia)

You shouldn’t be advertising: The role of the media. Women often talked about the information they had obtained from the media such as television and newspapers. In particular, television advertisements were frequently discussed. Their strength was seen in sparking interest and raising awareness. In addition, women recognized that the media played a major role in how

⁴ Quotes identifiers are (Participant number, Focus Group Number, Country).

information was dissipated, and “that the image of vaccines depends mostly on how the media plays it” (P5, FG1, Spain). As a consequence one needed to rely on one’s own active critical skills rather than be a passive recipient of advertising or news coverage. For example, the quote below illustrates how the information provided through advertising was seen as shallow and insufficient, which implied that one had to go beyond such superficial information to be truly informed.

“There was a lot of advertisements on TV, there was a craze, a lot of advertising on TV selling it but actually about information, they didn’t inform at all, [they told you] it just prevented the possibility of having cervical cancer but they didn’t tell you the cons or pros that the decision of getting the vaccine or not could have for you.” (P5, FG2, Spain)

Often the media were seen as “selling” the vaccine rather than providing information about it and this had a negative connotation. This idea was reinforced by presenting the vaccine in absolutely positive terms and in a commercial context. A common perception was that important medicines like the HPV vaccine were potentially life-saving and should not be sold akin to a commercial product by using emotions or an attractive appearance.

“I don’t think that the brochure must have a very attractive appearance, because its aim is not to sell a product, but mainly to inform.” (P1, FG1, Bulgaria)

Participants often “saw through” the advertiser’s intentions or recognized their influential techniques, labelling them as “manipulative” or “directed”. The overall negative perception of the commercialized vaccine is illustrated by the following discussion of an advertisement among Scottish participants:

“P4: I think it was like “arm against cervical cancer” or something (voices overlapping: yeah)...I think that’s what it was called, there was a chain of girls holding arms and it was all sorts of girls you know... just all sorts of people you know (laughing)...and I think that was quite appealing to the age group. P3: I think it was quite directed...which then to me I think that’s wrong, you shouldn't be advertising, you know thinking about the audience like that because it’s not a product, it’s er.. medical, you’re not trying to sell this!” (FG2, Scotland)

It’s here to convince: Transparency. Participants often commented that the information they encountered was unbalanced. What they meant was that it was presented purposefully in a biased fashion, or certain aspects were omitted, in order for the information to be more persuasive. Such information was evaluated unfavourably, while information which consisted of presenting both pros and cons was evaluated more favourably and as more trustworthy. Among the omissions mentioned were mainly the possible side effects of vaccination, or the fact that there are more strains of the virus than the vaccine protects you from. In that sense, presenting the vaccine as “100% protection” was seen as misleading.

[Commenting on a brochure] “Also this one, it seems that it’s here to convince that it’s necessary to get the vaccine, let’s say. It should also say different points of view, the side effects and all that. I see that it mostly supports a position.” (P2, FG1, Spain)

“I liked very much in that brochure that it said everything very realistically, and not to delude you, for example, that if you get vaccinated you will 100% be... It is directly described that they don’t guarantee.” (P3, FG2, Bulgaria)

When discussing what sort of information women wanted to receive about the virus and the vaccine again great emphasis was placed on transparency. This meant presenting facts in an open, unbiased fashion, as well as tailored to the needs of the recipients, such that it was understandable and adequate. For example, one woman expressed her desire to see more statistical information as opposed to persuasive appeals, or “fairy tales” as she referred to them with irony.

“Scientific, statistics, something very exact which can answer your questions in a more detailed way, not like a fairytale. Because brochures are like fairytales. This is great, absolutely, you will reinvent the wheel if you get the vaccine.” (P3, FG3, Bulgaria)

Find out for yourself: Active information search. Women’s perception was that they would not receive the necessary information about the vaccine unless they actively searched for it. Rather, they had to be pro-active and inform themselves.

“I think that there is information if you look for it, you know, if you have gone to get some information. If you haven’t gone to get information, no...” (P2, FG1, Spain)

Some of them reported “doing their own research” about the vaccine as the information they initially received was insufficient. On the one hand, it was perceived as routine to look for additional information, as not all the necessary knowledge could be conveyed in one source or be targeted to all sorts of recipients. However, some young women perceived that information was withheld, so that they would have to make an effort to get it. For example, one Bulgarian participant commented on her impression that Bulgarian doctors were reluctant to provide information unless you specifically asked about it:

“Now, to be honest, doctors here are like that: unless you ask about every single detail that you are concerned about, they will not start explaining and give you the information you need. You have to ask and find out for yourself. So it is questionable how much doctors are informing us.” (P2, FGI, Bulgaria)

We first investigate the doctor: Information sources and their reliability. Women discussed numerous sources of information, ranging from health professionals to people with experience with vaccination (see information sources analysis for further details). Among these, family and friends played a supportive rather than an informative role, except for when they were health professionals. Rumours and personal stories of people who got vaccinated were also pervasive, especially in the Spanish focus groups. Most significantly, gaining a second opinion was emphasised in the discussions. . In that sense, sources needed to be “triangulated” in order for the information to be verified. One example suggested by participants was searching for information on the Internet and then talking to one’s doctor.

Most importantly, information was not assimilated blindly. Rather, participants would evaluate the source’s trustworthiness and motives before making a decision based on the provided information. This included seeking “expert” opinion from someone who was seen as competent rather than trusting random posts on the Internet. It was recognized that even expert sources could be biased for various reasons (e.g., doctors having a contract with pharmaceutical companies). This was particularly the case in Serbian and Bulgarian discussions where health professionals were often mistrusted. One solution to this problem was to consult a doctor who had a personal connection to the family.

“I rely mainly on the opinions of relatives and family friends who are doctors or of similar profession, what should and what should not be necessary, which are bad and good sides of the vaccine.” (P2, FG1, Serbia)

“Well, we first investigate that doctor and see if he’s good. If he has a lot of patients...I, by the way, have investigated my personal gynaecologist through the Internet and I know that he is very good, so maybe I would trust him.” (P2, FG2, Bulgaria)

Risk Adjustment

This theme captures how participants acted on the information they had obtained and approached the decision about HPV vaccination. Very prominent in this theme was the tendency for risks and benefits to be strongly individualized in view of personal, generational, and societal factors. Certain aspects of the vaccine and the available information resulted in feelings of uncertainty. The core issues in this theme were mostly similar across countries. However, some of them were manifested in different ways in the Western and Eastern discussions. We elaborate on these cross-cultural differences below.

It depends: My risk, my benefits. When considering their decision regarding the HPV vaccine, women tended to talk about the risks of contracting HPV and the associated benefit of the vaccine in personal rather than in absolute terms. Risk perceptions were adjusted according to factors like age, sexual history and current relationship status. As women were mainly in their twenties, they considered the potential number of past sexual partners as indicative of the likelihood that they had already encountered the virus. This led to further discussions around doubts of the vaccine’s effectiveness for their age group.

“Now I’m thinking well it’s quite useless cos I’ve already had some sexual partners and I could have it already and I think smear tests are useful for that reason.” (P1, FGI, Scotland)

“Well, we are already sexually active, and you are supposed to get the vaccine before you become active, because then it is most....I forgot the word... most effective. Actually, at this point, you can’t be sure about the effectiveness of the vaccine.” (P2, FGI, Bulgaria)

Young women also considered the number of potential future sexual partners as indicative of the risk group they belonged to. In that sense, having one stable partner was seen as a means of risk reduction which rendered vaccination at that point less beneficial. This is illustrated by one Serbian participant who was considering what she would have done if she were offered the vaccine. She considered HPV vaccination strictly as “a matter of choice” because not everyone was at the same risk of infection; risk was individualized and dependent on lifestyle:

“First, you need to start with introducing some educational measures and then later to make it simple: a matter of choice. It depends on what kind of person you are. I do not know, maybe I wouldn’t have agreed, because I just know who I am, I do not let myself into relationships, how to put it... I do not have many partners.” (P3, FGI, Serbia)

What’s the use of it? Alternatives to vaccination. Women discussed alternative ways of protection for themselves, for the female population and society in general. In Spain and Scotland these were most often cervical screening with smear-tests and regular visits to the gynaecologist. Questions were often raised about the relationship between screening and vaccination, as well as possible “removal” of the virus if discovered through screening. For

example, one Spanish participant thought that the vaccine was useless if one had regular check-ups.

“Screening is something that might be...even more effective, then if you keep track you’re going to avoid it and all that. Had I known it earlier, we would have saved a lot of money from vaccines [laughter]. If I’m going to have my check, what’s the use of it?” (P3, FG2, Spain)

Sexual education and responsible sexual behaviour were seen as alternative means of protection for the young women themselves and for the population as a whole. This perspective was emphasized in Bulgaria and Serbia. Participants discussed ignorance about HPV and the HPV vaccine in the context of their societies: they identified the lack of sex education from an early age as the reason for the lack of awareness of sexually-transmitted infections. Education was seen as a way to promote responsible sexual behaviour, which in turn would reduce risks. However, for participants mass HPV vaccination was at an advanced stage of protection, which was still far away in view of the two countries’ lack of policies and lack of public awareness regarding STIs.

The joint influence of personal and societal factors in considering the benefits of vaccination against other alternatives is illustrated by two Bulgarian women:

“P1: [Reading off a brochure, turns to P3] Even if you get vaccinated, it is no guarantee and you have to continue with the screening. P3: Then what is the point of this vaccine? P1: So, 450 + 75 leva⁵ every month... P3: This is meant for a country whose health system is waaay ahead of ours.” (FG3, Bulgaria)

⁵ ~EUR265

We can't know: Uncertainty. Women's decisions regarding the vaccine were characterized by three dimensions of uncertainty. One concerned their personal judgment of the available information such as knowing whom to trust or what information is most important. This was very much related to the subtheme about information sources and their reliability, and its impact on decisions. The uncertainty relating to finding a competent and trustworthy information source is illustrated by a heated discussion among Spanish participants about the role of health professionals in providing information:

“P5: Nowadays you go to the doctor, or to the pharmacist, asking them about the human papillomavirus or about the vaccine and for sure they still don't know what to tell you. P3: And it's not only that, because if you go to the doctor you go to a place where you feel safe. P4: That's why I'm saying that I, if the doctor tells me about getting it and I get it because I trust him and that's it, but if I, for example, am not really sure because I might think, why is it that they give it to a type of person and the other...? You know? I can ask myself a thousand questions, then if I'm interested, because it's my health, I can also go to other, to other kind...P3: But it's supposed that these questions should be answered by the doctor? P4: It's supposed, you've said it yourself, it's supposed! P5: Come on, if the doctor doesn't answer them, where do you think you'd go?” (FG2, Spain)

Another type of uncertainty referred to the vaccine's side effects. In the Spanish and Scottish focus groups discussions of media reports about deaths or personal stories of people experiencing violent side effects were a frequent topic. While some participants disregarded these reports as “hyped up” or eventually discredited, for others they undermined the vaccine's credibility or made them reconsider the vaccine's benefits.

“I think that there are many side effects, which aren’t known. Only fever, dizziness, fainting are known. That there are a lot of others, that there are people who get paralysed or can even die and all that, and not a lot is known.” (P9, FG3, Spain)

“I go for it, because...I didn’t know the risks with a vaccine. I wasn’t really aware of them, but I figured side effects I can put up with it if the rest is beneficial...”(P2, FG2, Scotland)

Finally the vaccine’s novelty brought about feelings of uncertainty related to future consequences, especially among Western-European participants. Young women wanted vaccines that were 100% safe, well-tested, and approved. At the same time they recognized that the HPV vaccine had only been in use for a few years and that its long-term effects had not been established. On the one hand, this made some young women feel akin to “guinea pigs” and reject the vaccine. On the other hand, it was recognized that one generation had to be the first to take the risk for the greater final good. Some participants were under the impression that even experts had doubts, and this contributed to their uncertainty:

“But yeah it’s too new to say whether it is good or not. There should be further studies. The results of what is happening now should be released.”(P1, FG1, Scotland)

“Yes, yes, they [HPV vaccines] are a part of the immunization schedule already, and I think it’s rushed, that they should have researched more. Knowing that it isn’t, that the vaccine isn’t developed, knowing that you don’t know what can happen when you get it, putting it up on the schedule... And there are many doctors, the medical opinion has been divided because of that, because it’s been a big debate, and I think it’s very important that the medical opinion has been divided.” (P5, FG1, Spain)

Information source analysis

Participants brought up information sources on 134 occasions, with some participants discussing multiple sources and some discussing none. The information sources were grouped into 8 categories (see Table 3).

Table 3. Information sources, descriptions, and frequency with which they were discussed.

Source	Description	Frequency	Percent
Health professionals	Doctor, general practitioner, gynecologist, nurse, etc.	40	29.9
Internet	"The internet", Google, forums, general search without specification	25	18.7
Media	TV, news, newspapers, entertainment culture , TV commercials, advertisements	21	15.6
Family/friends	Mothers, friends, acquaintances, etc.	18	13.4
Family/friends who are health professionals	Mother who is a doctor, cousin who is a nurse, etc.	12	9.0
School	"In school" in general, listened to a talk at school	7	5.2
Scientific sources	Medical publications, scientists	7	5.2
People with experience	Vaccinated individuals, people who have decided about vaccination	4	3.0
Total		134	100.0

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Table 4. The number of times women in each country discussed having **obtained information** from each information source.

Source	Bulgaria		Scotland		Serbia		Spain		All countries	
	Count	%	Count	%	Count	%	Count	%	Count	%
Health professionals	2	15%	2	13%	3	38%	6	21%	13	20%
Internet	2	15%	2	13%	-	-	1	3%	5	8%
Media	5	38%	6	38%	2	25%	7	24%	20	30%
Family/friends	4	31%	1	6%	1	13%	10	34%	16	24%
Family/friends health professionals	-	-	2	13%	1	13%	2	7%	5	8%
School	-	-	2	13%	1	13%	3	10%	6	9%
Scientific sources	-	-	1	6%	-	-	-	-	1	2%
People with experience	-	-	-	-	-	-	-	-	-	-
Total	13	100%	16	100%	8	100%	29	100%	66	100%

Table 5. The number of times women in each country discussed that they would **prefer to consult** each information source.

Source	Bulgaria		Scotland		Serbia		Spain		All countries	
	Count	%	Count	%	Count	%	Count	%	Count	%
Health professionals	6	38%	4	29%	9	38%	8	57%	27	40%
Internet	7	44%	5	36%	5	21%	3	21%	20	29%
Media	-	-	-	-	1	4%	-	-	1	1%
Family/friends	1	6%	-	-	1	4%	-	-	2	3%
Family/friends health professionals	-	-	2	14%	5	21%	-	-	7	10%
School	-	-	-	-	-	-	1	7%	1	1%
Scientific sources	2	13%	3	21%	1	4%	-	-	6	9%
People with experience	-	-	-	-	2	8%	2	14%	4	6%
Total	16	100%	14	100%	24	100%	14	100%	68	100%

Table 4 shows the number of times women discussed having obtained information from each information source. Table 5 shows the number of times women discussed that they would prefer to consult each information source. On 66 (49%) instances young women discussed sources from which they obtained HPV-related information and on 68 (51%) instances sources from which they would prefer to obtain such information. Participants most often reported having received information from the media, family/friends, and health professionals. Interestingly, in the Spanish focus groups the most frequent source was family/friends. In the Serbian discussions women mentioned obtaining information from few sources overall. The most preferred source across all countries was health professionals, followed by searching on the Internet. The third category, surprisingly, was family or friends who are also health professionals, prominent in the Serbian focus groups. It is noteworthy that scientific sources emerged as a preferred category that participants would consult in three out of four countries.

Discussion

The goal of this paper was to explore the experiences of young women aged 18-26 with communication about the HPV vaccine. This included information and information sources about HPV and the HPV vaccine. Being well-informed about the risks and benefits associated with HPV and the vaccine is not only ethically desirable but also the first step towards vaccine uptake, as several health-behaviour models suggest [29, 42]. Qualitative, cross-cultural methodology allowed us to examine in depth the interplay between micro (individual) and macro level (societal) factors related to obtaining information about HPV [42]. Our participants were university educated women from four European countries with different vaccine implementation policies. This age group is especially interesting for two reasons. First, most vaccination policies focus on younger girls (11 to 14 years) and populations beyond this age are not eligible for mass

immunization. However, older girls and young women could still benefit from vaccination [12]. Second, this specific age group (18 to 26 years) offered insight into a variety of experiences. These included women who were vaccinated at an earlier age in a school vaccination program (Scotland) or via on-demand provision (Spain). Alongside this were women who had relatively less exposure to HPV campaigns (Bulgaria) or almost none (Serbia) [9]. Hence, a variety of social contexts (e.g., presence of a vaccination program), personal experiences (with information and vaccination), and opinions (pro, against or undecided) were represented in the discussions.

We identified several similar issues in women's discussions, which we grouped into two common themes. The first theme concerned **Critical Appraisal** of the available information. This referred to both the perceived quantity (sufficient or not) and quality evaluations (transparent or biased) of information. Overall, women perceived that they did not have sufficient knowledge to make an informed decision. Significantly, even women from countries where the HPV vaccine had received more state and media attention felt uninformed regarding essential aspects of the HPV vaccine. Problems with accessing information were particularly striking in Serbia, where the majority of women had no previous information about the vaccine (Table 1). Although we cannot conclude that our sample is representative of the general population, this finding reflects the state of HPV vaccine implementation in Serbia, where vaccination has never been officially recommended and initial campaigns have ceased [9]. In fact, this is the first study to our knowledge to address psychological issues related to HPV in any population in Serbia.

Although we did not assess women's knowledge per se but rather focused on their perception of the degree to which they were informed, we should note that there were common

misconceptions, doubts, and questions about the vaccine. These often related to the relationship between sexual activity and the vaccine's efficacy, the degree of risk reduction provided by the vaccine, and the necessity and benefits of screening in combination with vaccination. It might be useful in subsequent research to focus on identifying such questions, so that they can be properly addressed in information materials.

Our analysis of information sources revealed that information about HPV reached young women mainly through the common channels of social transmission (e.g., family and friends), advertisement, and health professionals. However, both the frequency and thematic analyses highlight differences between actual experience and preference for information sources. The most preferred information source was a health professional. This was, however, followed by an Internet search, which often included skimming through “everything that is out there” and selecting reliable information. This again highlights **women's preference for self-reliance and the ability to critically examine information.** However, it is not clear how well young women can actually identify high quality information on the Internet, or to what degree low quality information influences their decisions. Both the thematic and frequency analysis suggest the potential benefit of directing young women to neutral and credible sources where they can inform themselves in more detail. Future research should investigate what these sources could be depending on the context and how such a strategy influences decision making about the vaccine. For example, an international source provided by authorities perceived as trustworthy (e.g., on a European rather than national level) may be more effective in increasing trust in information. This may be particularly relevant in Eastern Europe where information provided on a local level might be met with scepticism. One potentially useful source in our opinion is the webpage of the European Cervical Cancer Association (<http://www.ecca.info/>) which offers the same essential

information in different languages. Future research can also investigate whether presenting the information about the vaccine using different information formats might improve risk comprehension and risk communication [43, 44].

Overall women in our sample were critical rather than naïve towards the information they encountered. Participants actively searched for information and preferred transparency: to them this meant presenting all facts (both pros and cons) in an unbiased fashion so that one could make an informed decision. In order to assess the transparency of information, young women considered two types of cues: the information provider's motives (are they genuinely interested in my well-being or are they trying to make money?) and the presence of both positive and negative information (both benefits and side-effects). Previous qualitative studies with young women focused mainly on identifying barriers and facilitators of vaccine acceptance (e.g., [28, 45]). Our thematic analysis with a focus on the HPV vaccine communication strategy revealed that common facilitators of vaccination like health provider recommendation occur within a context and could easily misfire if information is not perceived as transparent. Further, this can vary not only from person to person but also between contexts. Previous vaccination scares in the UK [46] for example, or the complex socio-cultural implications of a communist legacy in some Eastern European countries [30] can influence vaccination efforts. Furthermore, people might become mistrustful of health-care in general or be especially sensitive to trustworthiness cues in health information. A very striking example is the recent HPV campaign failure in post-communist Romania, where mistrust and conspiracy theories appeared to be the main reason that vaccination coverage did not go over 2.5% [29]. Such occurrences suggest that vaccine communication can be more effective if culturally-sensitive issues are anticipated and addressed. Furthermore, it might be useful to further explore culturally defined notions of information

transparency. While our analysis revealed that young women had common notions of transparency, transparency as a concept may be subjective. What is regarded as transparent information might constitute culturally-specific dimensions (for example, including information about particular aspects of a vaccination program might be perceived as more essential in some contexts than in others). How transparency is defined in different contexts requires further qualitative study.

Another noteworthy result was related to the commercial side of the vaccine. The image of the HPV vaccine as a commercial product sold on the market was seen as inappropriate and provoked negativity. The vaccine was regarded as a potentially life-saving product, to which everyone should have access. The high costs of this “product” contrasted with the healthcare systems of the European countries where the discussions took place, where primary care is free or insurance is relatively affordable. Further, this negative view of commercialism might not be restricted only to potential recipients of the vaccine. For instance, Bulgarian medical professionals expressed similar scepticism about the effectiveness of the vaccine and the profit behind it [47].

The second main theme was **Risk Adjustment**. It captured how the known risks and benefits were adjusted in view of personal (e.g., prospective sexual relations) and societal factors (e.g., availability of screening services). Mainly, the risk of contracting HPV was related to the number of partners. This led some women to conclude that a single or long term partner meant reduced risk. A similar finding with US participants was reported by Hopper and Clippard [45]: “Responses reflected the false belief, in many cases, that monogamy was protective” (p. 272). Our analysis, however, suggests that young women carefully considered the risks and benefits

their own situation entailed. Rather than feeling absolutely protected by monogamy, participants compared their risk of contracting HPV from the present to the risk of someone who would be exposed to more partners. In that sense, the vaccine offered less benefit to them at this age and this benefit had to compete with the numerous vaccination costs. These costs included the monetary cost as well as the psychological costs related to informing oneself properly and running additional risks associated with side effects.

There were some notable differences between countries in discussing alternatives and potential uncertainties related to vaccination. Regular screening as an alternative to vaccination was more widely discussed in Scotland and Spain, while educating the public about health-protective behaviours and STIs in general was more prominent in the Bulgarian and Serbian discussions. Further, issues about vaccine novelty, media stories about dangerous vaccine side effects or rumours about people experiencing them were present in the two Western discussions but not in the discussions from the Eastern European countries. These differences might be rooted in the nature and degree of information exposure in these countries. This was supported by the frequency analysis of information sources, showing that the media and social transmission were more common ways to receive information among Scottish and Spanish participants surpassing health professionals. Further, Scotland and Spain have already witnessed HPV vaccination campaigns. Hence, it is to be expected that young women would be more aware of HPV and screening overall, while the participants from Eastern Europe attributed the absence of information to lack of education and support by the state. Similarly, the media in Scotland and Spain were more likely to reflect on potential HPV vaccination scares, while HPV was less reported in the Bulgarian and Serbian media at the time because of the absence of national policies. In that sense, some issues related to vaccine resistance might not only be specific to

cultural context but specific to implementation stage. If this is the case, it might be strategic for authorities to anticipate and counteract exaggerated vaccine resistance with appropriate risk communication. Shortly after this research project was finalized the Bulgarian Ministry of Health adopted a vaccination program targeting teenage girls [9]. It will be interesting to see if as implementation progresses, similar issues to those in Scotland and Spain arise in Bulgarian discussion about HPV.

Overall our results emphasized the multifaceted role of information acquisition and evaluation in vaccination decision making. This is supported by the Information-Motivation-Behavioral Skills Model (IMB) [42]. The IMB model goes beyond traditional motivational models and incorporates the role of vaccine-related information, along motivation and behavioural skills in vaccine uptake. Applied to the context of HPV vaccination, the model states that individuals who are well-informed, motivated to act, and possess the relevant behavioural skills are likely to get vaccinated. The IMB model also incorporates the influence of macro-level factors like ethnicity or vaccine cost. Within the framework of the IMB model, our research focused on the role of HPV vaccine information and explored its interplay with such macro-level factors (e.g., media coverage, socio-cultural context, and trust in authorities). The IMB model can be further adapted to accommodate these and other relevant macro-level factors identified by qualitative inquiry and examine their influence on individual decision making in a quantitative paradigm. The IMB model also emphasizes that skills such as securing funding or negotiating health care provider support are essential for vaccine uptake. Our analysis shows that women utilize similar skills even at the earlier pre-decision stage of information acquisition as captured by the theme **Critical Appraisal**. These might include the ability to search for information and to evaluate the credibility of information sources.

There are a few typical limitations and strengths inherent to this type of methodology that should be noted. First, we relied on volunteers to participate in the discussions, which might have attracted participants with a strong opinion about the HPV vaccine. However, the fact that there were participants who had no prior information about the HPV vaccine in all countries but Scotland speaks against this possibility. Second, some original meanings might have been lost after translating the transcripts into English. In order to minimize this problem, we involved native speakers in the analysis, used multiple coders, and chose an analytical procedure which is not highly sensitive to language use [40]. On the other hand, one major advantage of qualitative methods is that participants' answers are less constrained by the researcher's perspective. This provides the opportunity to discover in depth issues important to participants that might not have occurred to researchers (e.g., [48]) and to consider participants' reflections in their broader socio-cultural context.

Conclusion

HPV is the most frequent sexually-transmitted infection worldwide and a cause of cervical cancer [3]. The HPV vaccine is potentially one way to reduce cervical cancer incidence but questions and challenges to implementation remain [21]. Informing the public is an essential and ethically desirable step to prevention. However, recent analyses in Europe [22], the US [49], and Canada [24] reveal that information about HPV might be suboptimal and inaccurate even when provided by official authorities. It is not yet clear how the public deals with such information. Our qualitative, thematic analysis demonstrated that the 54 young university educated women who participated in our discussions took most information about the HPV vaccine with a grain of salt: They evaluated the quality of information and preferred transparent

to selective or biased reporting. This suggests that it would be beneficial to direct young women to credible, high-quality information sources they can consult on their own or encourage consultation with a health professional, who was still regarded as the most preferred information source. However, the question remains as to how less privileged groups deal with information. In addition, young women considered the decision to vaccinate against HPV at their age (18 to 26 years) as highly individualized; they considered their lifestyle and potential alternatives to vaccination; they also recognized the uncertainty related to making a decision in view of (un)regulated communication of evidence and uncertainty inherent with new vaccines. Last, the cultural context influenced women's exposure to information and shaped their perceptions of vaccine relevance and safety.

Conflict of Interest

The authors declare no conflict of interest.

Acknowledgments

Dafina Petrova contributed to data collection, analysis, and preparation of the manuscript. Carol Gray Brunton was the principal investigator and contributed to the study's design, data collection, analysis, and preparation of the manuscript. Moritz Jaeger contributed to data analysis and preparation of the manuscript. Anita Lenneis contributed to data analysis. Rocio Muñoz contributed to data collection and analysis. Rocio Garcia-Retamero and Irina Todorova contributed to the preparation of the manuscript.

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