

**CONTEXTUAL CONSTITUTION OF BEHAVIOR:  
INTRODUCING THE HPV VACCINE IN EASTERN  
EUROPE**

*An NCEEER Working Paper by*

**Irina Todorova**, Northeastern University  
and  
**Adriana Baban**, Babes-Bolyai University



**National Council for Eurasian  
and East European Research**  
University of Washington  
Box 353650  
Seattle, WA 98195  
info@nceeer.org  
<http://www.nceeer.org/>



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## **Executive Summary**

We are in a time in which we can observe the initial introduction of a much debated new pharmaceutical – the HPV vaccine for the potential prevention of cancers in men and women. The vaccine embodies a vast array of personal and cultural meanings and discourses, including those of responsibility, control, morality, gender, and sexual behavior. It also represents multiple interests of many actors (adolescents, parents, physicians, pharmaceutical companies, policymakers). Their attitudes vary depending on local meanings of sexuality, religious beliefs, stigma, their experiences and trust in the health care system. People are not showing up for vaccination in the numbers that public health officials would like to see, or are refusing to administer it to their children. This situation offers the opportunity to explore the importance of context in explaining and understanding people’s motivations and decisions for health-related behaviors and particularly - vaccination. Health behaviors are understandable or “acquire meaning and significance on the basis of their relationship to the broader social practices” (Mielewczyk & Willig, 2007). In this sense, people’s decisions regarding health protective behaviors might not conform to rationalistic understandings, or might seem “irrational” or ‘misinformed’, yet make sense when considering the situations which are constitutive of them and the symbolic meanings which they embody. In this paper we will discuss the contextual aspects of attitudes and behaviors of prevention, disparities in access and implications for prevention, particularly through vaccination with the HPV vaccine. We will address the relevance of history, healthcare policy and gendered attitudes in Eastern Europe, for the constitution of preventive attitudes and behaviors.

## **Introduction**

We are at a time in which we can observe the initial introduction of an important new pharmaceutical – the HPV vaccine – which can offer particularly valuable insight into the psychosocial, cultural and political landscapes of societies. The vaccine embodies a vast array of personal and cultural meanings and discourses, including those of gender and sexuality (Carpenter & Casper, 2009), masculinity and femininity, sexual behavior, as well as morality, responsibility and power. It is situated in multiple discourses, interests and attitudes of many actors (adolescents, parents, physicians, pharmaceutical companies, policymakers). Proponents hail it as a major public health innovation that will reduce HPV infection and transmission, cervical cancer incidence, as well as other HPV related problems. Critics point out its newness, unclear long-term efficacy and side-effects, its potential to alter future screening practices and undermine financing of screening programs, etc. While some hope that the vaccine will also contribute to eliminating historic disparities in cervical cancer incidence and mortality among population groups (Tsu & Levin, 2008), others are concerned that it deepens disparities or that it can mask structural reasons for disparities (since it pushes screening and its dependence on a smoothly functioning health system to the background).

Thus, the introduction of the HPV vaccine has changed the scene of cancer prevention for men and women and has ignited optimism for the elimination of the disease, as well as diverse and animated debates. Attitudes and meanings regarding new approaches to prevention are contextual and shaped by conceptualizations of trust, responsibility, control, and gender. In this paper we will discuss the contextual aspects of prevention with the HPV vaccine.

## **Background**

### *Attitudes and Behaviors in Context and Prevention of Cancer*

The importance of context in explaining and understanding people's motivations and decisions for particular health-related behaviors, including cancer prevention, is being more frequently underscored. Showing up for HPV vaccination for self or daughters/sons are preventive behaviors, taking place within complicated social and cultural contexts.

Health behavior models have been widely used in understanding and predicting multiple preventive behaviors and intentions, including screening (Bish, Sutton, & Golombok, 2000; Sutton & Rutherford, 2005) and HPV vaccination behavior and intentions (Brewer & Fazekas, 2007). Yet, their ability to predict behavior has been shown to be limited (Mielewczyk & Willig, 2007). Moreover, the relevance to health behavior models across different sociocultural contexts has been rarely addressed (Stewart, Rakowski, & Pasick, 2009). When it has, some of the central constructs of these models, such as beliefs about susceptibility to the disease, or about benefits of the behaviors, have been shown to predict behaviors in similar ways in different ethnic groups, however other constructs such as intentions have not shown such wide applicability (Stewart, et al., 2009). Thus, it is important to underscore the need to understand the meaning of such constructs, as well as broader meanings of illness, prevention, screening and vaccination within particular contexts through in-depth inductive research (Burke, Joseph, Pasick, & Barker, 2009) or combined and mutually informed inductive and deductive research (Pasick et al., 2009).

The perspective we use is one according to which health behaviors are understandable or “acquire meaning and significance on the basis of their relationship to the broader social practices” (Mielewczyk & Willig, 2007). Thus, to understand why some people decide to or not

to vaccinate their children with the newly developed HPV vaccine would become clearer, and thus inform relevant health promotion, if we delineate the complex social practices and meanings in which these behaviors are embedded and through which they are constituted (Mielewczyk & Willig, 2007).

In this sense, people's decisions regarding health protective behaviors might not conform to rationalistic understandings, or might seem "irrational" or "misinformed", yet make sense when considering the situations which are constitutive of them and symbolic meanings which they embody. We know that people continue with health risk behaviors even when they have the necessary information – since risk behaviors, or avoidance of health promoting behaviors (such as screening and vaccination) can have "important symbolic meanings", be relevant to social identities and be constituted in social interactions and structures, and thus have "wider social explanations" (Stephens, 2011). There are different ways to go about understanding this, and certainly narrative approaches are particularly appropriate and we have used them extensively in the work we will be describing.

### *Cervical Cancer Prevalence and Prevention*

Cervical cancer is one of the leading causes of death for women worldwide (Gakidou, Nordhagen, & Obermeyer, 2008). Mortality rates have been falling, but cervical cancer continues to be an important public health problem with disproportionate impact on women of lower socioeconomic resources (Garner, 2003; Newmann & Garner, 2005; Singh, Miller, Hankey, & Edwards, 2004). About 86% of the cases occur in developing countries, representing 13% of female cancers." (American Cancer Society, 2011; WHO/ICO Information Centre on HPV and Cervical Cancer, 2010). In some areas (such as sub-Saharan Africa) (Ramogola-Masire, 2010),

cervical cancer is the leading cause of cancer deaths among women.

Secondary prevention of cervical cancer has been extremely successful – it is carried out through the Papanicolaou (PAP) test, aimed at detecting early cellular abnormalities. Early diagnosis and treatment of cervical lesions leads to eliminating progression into cancer and reducing morbidity and mortality rates.

Yet, between and within country disparities in cervical cancer mortality are striking. Instead of falling, as in many other countries of Eastern and most countries of Western Europe, cervical cancer morbidity and mortality rates in Bulgaria and Romania have been steadily rising during the last three decades<sup>1</sup> (Figure 1).

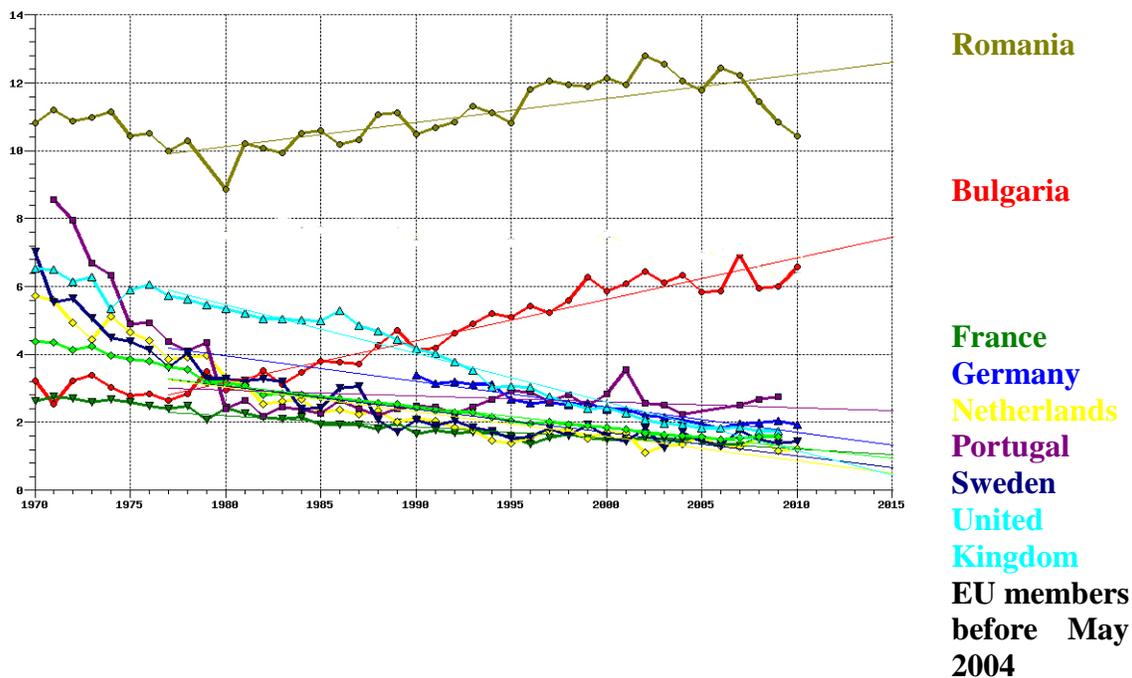


Fig. 1. Mortality Rates from Cervical Cancer, Per 100,000 women; Ages 0- 64; WHO Health for All

For the last 20 years, Romania has had the highest cervical cancer mortality in Europe, with rates 6.3 times higher than the average of EU. In Bulgaria, mortality from cervical cancer

<sup>1</sup> Data on incidence and mortality are from the WHO Health for All Database: <http://data.euro.who.int/hfad/>

has nearly doubled from 1980 to 2010, currently being three times the EU rate. A possible explanation for these disparities in Bulgaria and Romania are that population based screening programs characteristic for Bulgaria since the 1970's were dismantled after 1989; Romania did not have a population based screening program until 2012, when a National Screening Program was launched for women 25-64 years of age. Thus rates of screening are relatively low. In our representative samples in Bulgaria (49.5%) and Romania (20.2%) of women had ever had a Pap smear, and there were evident disparities among different ethnic groups (Avramova et al., 2005; Baban et al., 2005):

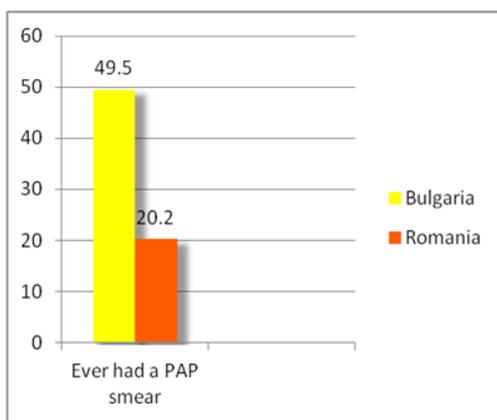


Fig. 2 Screening history in Bulgaria and Romania

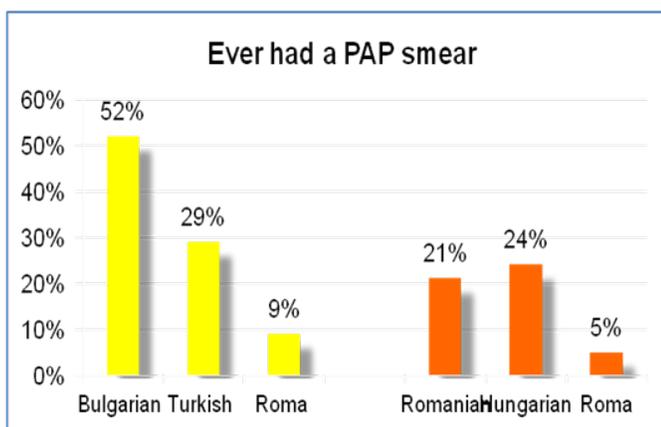


Fig. 3. Screening history disparities for different ethnic groups in Bulgaria and Romania

### Primary Prevention

Though secondary prevention through PAP smears is highly successful (success is evident in countries with high resources), cervical cancer continues to be a high burden worldwide and to exhibit high inequalities. Among other reasons, this is due to the difficulties in designing, implementing, financing and sustaining population based screening programs, or even highly effective opportunistic approaches.

In the mid-1980's it was shown that cervical cancer is caused by the Human Papilloma

Virus (HPV), and it is now known that the HPV is transmitted mainly through sexual contact (but also through intimate skin contact and also through vertical mother-child transmission). The predominantly sexual nature of the transmission of HPV transformed cervical cancer into a sexually transmitted disease and thus altered public attitudes, debates, and policies, as well as introduced new primary preventive methods.

Thus, primary prevention of HPV infections (and by extension potentially of HPV – related cancers) is now believed to be possible. This is through a newly introduced preventive technology – the HPV vaccine. This vaccine prevents infection with HPV, and is expected to be instrumental in the primary prevention of cervical cancer and other conditions also caused by the HPV virus such as different genital, head and neck cancers in men and women. Not surprisingly, the introduction of the vaccine has caused much excitement and hope in the area of cancer prevention – the vaccine has been hailed as “revolutionary”, a ‘remarkable achievement of medicine and public health’, “The first vaccine expressly directed at cancer prevention” (Bonanni et al., 2011).

Currently two vaccines are being used<sup>2</sup>, which are usually approved for girls and women 9-26 years of age; programs are being discussed to extend vaccination to other populations, including adult women and men (who are not current carriers of HPV) (King et al., 2008; WHO, 2008). The vaccines are administered in three doses over 6 months (European Centre for Disease Prevention and Control, 2008).

The vaccines Gardasil (as Silgard) and Cervarix were introduced in Bulgaria and Romania in 2007-2008. Vaccination policies in both countries were different, and changed recently and have significant implications for attitudes and local atmospheres. These changes

<sup>2</sup> Gardasil, a vaccine against four strains of the HPV virus, manufactured by Merck (& Sanofi Pasteur, the European branch of Merck); and Cervarix, manufactured by GlaxoSmithKline.

happened during our study and allowed us to follow the implication of policy revisions. The policy in Romania changed from free provision, to dismantling of the program with now practically no available vaccines on the market. The policy in Bulgaria changed from private to free provision for 12 year old girls. In both countries the vaccine is in the recommended vaccination calendar (not the mandated). However, in Romania, when it became clear that the program was not working, it was changed from an opt-in to an opt-out format, before finally being dismantled.

At first glance the HPV vaccine is a simple phenomenon – the world’s first vaccine to “prevent cancer” should be beneficial if it will reduce the burden of mortality of HPV related cancers, and particularly cervical cancer which disproportionately falls on women with the fewest resources. When analyzing the different perspectives on the vaccine and the practice of vaccination in greater detail, we see that it actually elicits much uncertainty and confusion.

### *Parental Acceptance and Resistance Toward the Vaccine*

In this situation, clearly questions of uptake of this relatively new technology for primary prevention are taking center stage – the psychosocial and cultural aspects of which are most relevant to our discussion. People are not showing up for vaccination in the numbers that public health officials would like to see, or are they are refusing to administer it to their children. This has stimulated active research on parents’ attitudes and beliefs about the vaccine, using different methodologies (Bartlett & Peterson, 2011; Brewer et al., 2007; Brewer & Fazekas, 2007; Brewer et al., 2011; Trim, Nagji, Elit, & Roy, 2012).

Most studies have addressed parental (and to some extent young people’s) attitudes toward vaccination with the HPV vaccine, and intentions for vaccination. Intentions do not

necessarily translate to vaccination behavior – for example, in a longitudinal study (Brewer, et al., 2011), the authors found that of the parents who stated they intend to have their daughters vaccinating in 2008, by the follow-up in 2009, only 38% has done so. Of the recently published reviews, two reviewed papers on vaccination behavior (Bartlett & Peterson, 2011; Kessels et al., 2012), and one reviewed papers measuring either vaccination intentions or behavior (Trim, et al., 2012). The main issues regarding vaccine uptake, identified by Bartlett et al (2011) were related to: provider recommendation; parents’ knowledge, perceptions and attitudes toward HPV; and health care services. Parental concerns about the safety of the vaccine and adverse reactions were a central barrier in most of the papers reviewed; as well as the need for more information. Physician recommendation was also identified as important for uptake. By 2012 Trim et al (2012) were able to also address trends with time - in vaccination behavior, parental knowledge, attitudes and factors affecting decisions for vaccination(Trim, et al., 2012). These authors state that “parental experiences and demographic characteristics were too mixed to show any clear pattern” regarding factors affecting decisions and parental barriers to vaccination.

Another review by Brewer and Fazekas (2007) shows many factors contributing to HPV acceptability. Perceived effectiveness of the vaccine was addressed and shown to be a key predictor of acceptability (this is considered especially important for the HPV vaccine because of its relevance to STD); low perceived vaccine safety was identified as an important barrier. Physician recommendation was again determined to be an important predictor of intentions (Brewer & Fazekas, 2007).

In summary, existing studies on acceptability of the vaccine among parents show an absence of consistency and mixed findings regarding predictors of HPV vaccination behavior. The existing reviews stress the importance of cross-cultural differences. Qualitative studies similarly

show differences between studies, and illustrate the multiple issues that come into play in the construction of the HPV vaccine and its meanings. Conclusions vary, since constructions are varied, local and historical. Recently in a special issue on cancer some of the overall conclusions made from the papers were regarding “the great need to broaden behavioral medicine research in cancer to countries that have the greatest morbidity and mortality from the disease, and the importance and utility of considering the cultural relevance of psychosocial and behavioral constructs.”(Antoni, 2011). Similarly, another relevant special issue on health protective behaviors in relation to emerging infections (Vaughan, 2011) states that “contemporary perspectives take into account broader influences [on vaccine uptake] such as emotions, social processes, cultural values or beliefs, socioeconomic conditions, trust in public health authorities...”.

Thus we can conclude that (HPV) vaccine behaviors are not ‘discrete’, isolated, one-time decisions, but are complex behavioral, moral, value-related and contextual (political, social and cultural phenomena) , which have rarely been fully explored as such.

## **Methods**

The studies were approved by Ethics Committees at Northeastern University, in Romania by the Ethics Committee of Public Health and in Bulgaria by the Bulgarian Psychology Society. We collected data in Romania and Bulgaria through several approaches (Table 1). The data collection methods included semi-structured interviews with women in each country; semi-structured interviews with healthcare providers in each country who provide screening and vaccination; semi-structured interviews with key informants in each country, including representatives from the Ministry of Health, Oncological Institutions, Professional Societies, The

National Health Insurance Funds, pharmaceutical companies and others; focus groups with parents (3 focus groups/in each country); documents from the National Oncological Programs, the Ministries of Health, publications in the media, and documents from pharmaceutical companies regarding the HPV vaccine.

**Table 1.** Sample Description

<b>Bulgaria</b>			<b>Romania</b>		<b>Analysis</b>
	<b>Total N</b>		<b>Total N</b>		
Focus groups: 3	24	15 women 9 men	18	16 women, 2 men	Thematic Analysis & Discourse Analysis  Atlas.ti
Interviews with parents	11	11 women	11	11 women	
Interviews with health providers	12	7 women 5 men	12	12 women	
Interviews with Policy Makers	8	4 women 4 men	7	4 women 3 men	
Media materials	271 news stories published online between 2007 and 2012		150 news stories published online between 2007 and 2012		Content Analysis & Discourse Analysis

The interviews and focus group discussions were audio-recorded and transcribed verbatim in the original language. The qualitative data analysis was conducted in the original language, using Atlas.ti software. The collected interviews, documents, media publications and focus group transcripts analyzed through thematic analysis, with a special focus on language, informed by discourse analytic approaches (Braun & Clarke, 2006; Starks & Brown Trinidad, 2007).

## Results

The behaviors of vaccination or refusing vaccination have their specific local manifestations. To illustrate some of these we will address three dimensions of the context in which vaccination behaviors are constituted:

- \* **Danger**
  - Contradictory information creates uncertainty (incl. information they receive from providers)
  - Distrust and suspicion (health care system, relationships with providers)
  - Historical context
- \* **Gender**
  - Gendering the vaccine
  - Constructing the sexual nature of transmission
  - Inequities in responsibility
- \* **Structure**
  - Health system functioning and policies
  - Mandating vaccination vs. parental choice
  - Politics

### *Danger*

Yesterday however I had to go to the doctor and he said that there's no danger and that many vaccinations have been done, and there are no problems. I'm planning to do it, but when...to be honest I'm still afraid, and [the vaccine] is still sitting there in the fridge.  
(22 year old woman, Bulgaria)

The HPV vaccine is relatively new, and while information and availability have expanded quickly, it has not reached everyone equally. Limited availability of information, frightening information, or contradictory information, available from multiple internet sources, has led to uncertainty, perceptions of danger and fear (Penta & Baban, 2012). Discussions of the dangers are widely visible on internet forums, and in this medium greatly overwhelm any discussions of benefits. People's concerns about safety include concerns about side-effects at the moment of vaccination, long-term side effects which are yet to emerge, fear of infertility, of death and

others. Parents in Bulgaria point out that in the context of this limited and contradictory information, they have to 'chase' their providers to acquire information. Providers themselves however have different positions regarding the vaccine, ranging from celebratory mainly in pediatricians, through nuanced, to extreme negativity and contradict each other (Todorova, Panayotova, Alexandrova-Karamanova, & Dimitrova, 2012a). Even in Romania, where a program for free vaccination of the cohorts of girls was introduced as early as 2006, information has been limited or confusing (Baban, Craciun, & Penta, 2012). People felt they have unclear information about the mechanism through which the vaccine works, efficacy of the vaccine, safety and side effects, the schedule through which it is applied. Ultimately, Romania parents rejected the vaccine so widely, that the National program for primary prevention has been cancelled (Baban, et al., 2012).

In addition to the contradictory information available from the sources they heard, perceptions of the vaccine were shaped by embedded mistrust of the healthcare system and sometimes of providers. Mistrust was evident in both Bulgaria and Romania, but was particular intense for the Romanian women. Most medical systems in Central and Eastern Europe faced similar challenges during the communist regime and have struggled to implement new health care reforms in the 1990s. The Romanian healthcare system is nonetheless characterized by a unique mixture of political instability, financial constraints and unpredictability of the health reform. Moreover, the national medical system is perceived both by the general public and by the media reports as a system on the edge of collapse, marked by corruption and by inability to provide good quality services. The events happening over the last 20 years resulted in a chronic loss of trust in the capacity of the medical professionals and policy makers to provide constructive solutions compatible with the health care needs of the community (Spanu, Baban,

Bria, & Dumitrascu, In press).

The context of suspicion and mistrust has led to the development of conspiracy theories among potential users of the vaccine, according to which local or global conspiracies surround the introduction of the vaccine. In Romania these theories were provoked by the free provision of the vaccine - people saw themselves as experimental objects, as used by powerful forces to develop better pharmaceuticals or even to reduce the world population (Baban, et al., 2012). In Bulgaria on the other side, the conspiracy theories were provoked by the high price of the vaccine – they were fueled by perceptions of excessive corruption in levels of government, and by the assumption that its high price offers opportunity for illegal profit for officials promoting it. Parents are skeptical because of the samples and percentages given to providers from the pharmaceutical companies (Todorova, Panayotova, Alexandrova-Karamanova, & Dimitrova, 2012b). The producing companies and any of their messages were also regarded with suspicion considering the high price and potential profit for them.

Further, many doubted the safety not of the vaccine in general, but particularly of the vaccine that is being offered on the Bulgaria and Romanian market. Assumptions were that while "out there in the West" the vaccines were adequately tested and monitored, those making their way into Eastern Europe, they can be contaminated, or of low quality. These suspicions illustrate and intensify the existing social comparisons that people in Eastern Europe make in relation to Western Europe.

We see what is happening –medications are withdrawn because there is something wrong with them. There is nothing that we haven't seen, and this is not unimportant – people have no trust, that's it. (44 year old woman, Sofia)

There is very little information, which is brought out, and so the companies, which

manufacture the vaccine – they use people’s ignorance to...yes, I will say it, to push their vaccines, which are a large profit. (55 year old woman, Bulgaria)

Such mistrust is understandable in current contexts of health care reform in CEE, where people feel that constant changes have created chaos, depersonalization and commercialization of healthcare. In Romania for example the current distrust is also supported by the evaluation of the recently implemented vaccination program as unsuccessful, as an example of the ineffectiveness of the health-care system, and the way in which policies are disrespectful of people’s rights to information and decisions.

Mistrust can also be seen as resonating in the historical legacy of countries and societies. The historical context in Eastern Europe has included for example long periods in which clear personal or general health information has been absent or withheld<sup>3</sup> by institutions and providers. Important historical dimensions include also the enforced monitoring of women’s reproductive behavior in Romania, close monitoring of pregnancies to ensure that no abortions are performed (Baban, 2000; Baban & David, 1994; David & Baban, 1996). All socialist states instituted pronatalist policies as a means to ensure reproduction of the labor force. However, under Ceausescu regime the maximization of women’s reproductive capacities became the political objective of legislation. For the 23 years (1966-1989) Romania pursued the world’s most rigidly enforced pronatalist population policy expressed in Ceasuescu’ statement: “the fetus is the socialist property of the whole society and giving birth is a patriotic duty”. At the same time, import, sale and use of contraceptives was prohibited, and abortion providers were subject

<sup>3</sup> Particularly information about cancer – in Bulgaria there was a taboo on talk about cancer in general based on fear, and long tradition of hiding cancer diagnosis from patients.

to imprisonment, as were women found to have had an illegal abortion<sup>4</sup>. By 1989, the maternal mortality in Romania was ten times higher than the highest figure ever recorded in Europe. By denying women rights to reproductive health and means to control their fertility, the state produced the highest maternal and infant mortality rates in Europe, not to mention chronic distrust in state (Baban & David, 1994; David & Baban, 1996) . The individual and collective memories are still shaped by recall of traumas associated with sexuality and the wish to control fertility. Even after the political and economic reforms, the negative legacies of distrust, suspicion, and lack of cooperation still prevail - thus health educators and health providers have the uneasy task of working in this context. Current economic uncertainty, combined with the patriarchal organization of gender relations and institutions, exacerbated by years of rule by a paternalist state, make it difficult to translate new health policies and legal rights into equal opportunities and responsibilities for women and men alike.

The role of trust/ distrust in shaping attitudes and behaviors regarding vaccines has been addressed in a few other studies. (Bynum, Brandt, Friedman, Annang, & Tanner, 2011; Marek et al., 2011; Marlow, Waller, & Wardle, 2007; McAlearney et al., 2012{Marek, 2011 #298}). A study in Hungary on acceptability of the HPV vaccine revealed absence of information, but also high levels of distrust in the health system and in health specialists in Hungary (Marek, et al., 2011). An analysis of the resistance to another vaccination campaign (polio) in Africa,

<sup>4</sup> By the 1980s, having four children was no longer sufficient reason to ask permission for a legal abortion; to get permission for it, a woman had to have five living children, all under the age of 18. The extent to which the state attempted to control women's reproductive capacity and to transform their bodies into instruments in the service of the nation is reflected also by the political and legal machinery created to enforce its demographic policies. For example, employed women between 16 and 45 were required to undergo regular gynecological examinations in the work place. Those who refused to appear could lose their right to medical care, pensions and social security. To meet the norm, doctors had to perform 50-60 gynecological examinations a day to cover a factory population in a specified period of time, and their full monthly salaries depended if they had achieved a state-stipulated monthly birth quota. Medical procedures and health professionals were watched closely to ensure compliance with the law. The repressive regulation forced many women suffering complications from clandestine abortions to stay away from hospitals for treatment, thus risking permanent injury to their health, or often death. More than 10,000 women died during the 20 years of pronatalist policy of the Ceusecu's regime.

specifically Northern Nigeria, also illustrated the existence of conspiracy theories and distrust (Adams & Salter, 2007). The authors interpret the resistance through the “collective memory of racism” and “conquest and exploitation”, as well as in current experiences of unequal treatment in health institutions – and thus show how it is locally meaningful.

In summary, a rejection of the HPV vaccine can make sense from the perspective of parents, who see it as part of the existing manipulation of people by different institutions, pharmaceutical giants, and providers motivated by extra profits and this shapes attitudes and behaviors in Bulgaria and Romania. In this context, vaccination can take on meanings of danger, and thus avoidance of the behavior makes contextual sense.

### *Gender*

The preventive aspect of vaccination is to do it without any indications [of disease]. The indication is only gender, i.e. being a girl, that’s why you get vaccinated. (Female Gynecologist, Bulgaria)

Attitudes and behaviors of vaccination are constituted in local constructions of gender, and gendered responsibility for health. A peculiarity of the HPV vaccine is that it is only the second vaccine<sup>5</sup> to be (initially) recommended for only half of the population – and the first vaccine for a sexually transmitted virus to be recommended only to girls. Adolescent girls were the first to take on the risks and to be offered the protection of the vaccine, and thus were implicitly or explicitly imbued with responsibility for transmission of the virus. At the same time, boys and men are also carriers and transmitters of the HPV virus, and can also develop HPV-related genital, head and neck cancers.

<sup>5</sup> The Rubella vaccine was first given only to women and girls (since it is dangerous only to pregnant women), and then extended to boys, to achieve community immunity.

Vaccinating boys became realistic in the US when it became clearly a matter of health benefit for boys and report of genital, anal, throat and neck cancers are on the rise (Barroso & Wilkin, 2011). Previously, consideration of vaccination of boys were framed as a noble gesture for them to protect girls, even though they were not at risk of cervical cancer. There is still controversy on cost-effectiveness for vaccinating boys, academic publications using different models give different conclusions (British Medical Journal debate: BMJ, 2009, 339; b4921.) However, while cost effectiveness is debated, ethical evaluations of the one gender policy have deemed it as “perpetuating gender role stereotypes, reinforcing the idea that STDs are a women’s issue”, and a “failure to genuinely engage boys in this program is a missed opportunity to address gender equity”(Rae & Kerridge, 2011).

The sexual nature of transmission is generally muted in provider discourses, in public health messages, as well as marketing messages, which perpetuate the image of “a girls’ vaccine”. The construction is of a vaccine for cancer (particularly cervical), rather than for a sexual/relationally transmitted condition – leads to individualizing choice and responsibility. Merck’s marketing campaign for “One –Less victim” inadvertently symbolizes the individualized approach of marketing, the construction of the disease as individualized (i.e. cancer) rather than relational (STD) and the construction of choice as individualized (Mishra & Graham, 2012; Thompson, 2010).

The HPV is not widely discussed as associated with health problems in boys - neither by the health professionals, nor by the parents in Bulgaria and Romania. In the words of one of the mothers in Bulgaria “Oh, no, what does cervical cancer have to do with boys?!” (45 year old mother with 17 year old girl). After consideration, some of the mothers were open to vaccinating their boys in the name of shared responsibility – they do not connect HPV to potential cancers in

boys, so they construct this as a gesture to protect girls

While understanding the medical reasons for vaccinating boys, providers were skeptical about including them in vaccination procedures, expressing more or less a pragmatic attitude. They stated that even though the vaccine is indicated and available for girls and boys, vaccinating boys is not cost effective and not realistic in the Bulgarian cultural and financial situation. They insisted on “fighting for what is realistic” at this moment – i.e. developing a national policy for vaccinating girls. With this, however, they reinforce the discourses of juxtaposing men and women, stereotyping gender roles, constructing STDs as individual responsibility and re-instating women’s responsibility for sexual behavior and health.

Bulgarian health providers describe the vaccine as a pharmaceutical product preventing against cervical cancer and the SDT reference is cautiously avoided. Thus, the discomfort that issues related to sexuality and STDs might bring to parents when recommending vaccination to their children are avoided by the health professionals (Dimitrova, Panayotova, Alexandrova-Karamanova, & Todorova, 2012). As one gynecologist states: “...the father, needs to accept that his daughter is sexually active” (Gynecologists, Plovdiv).

None of the health professionals participating in our study discussed the preventive effect of the vaccine for sexually-transmitted infections other than cervical cancer. The phrase “every day one woman dies from cervical cancer in Bulgaria” succinctly presents the benefits from it in term of saving lives and is repeated by the HPs in almost all of the interviews. This image of the product as a “vaccine against cancer”, and in particular cervical cancer, has important implications for the image of the vaccine in the public understandings.

[In Bulgaria] every day one woman dies from cervical cancer, this is something very scary.

If people hear it and understand it, I think they can prevent it, by getting vaccinated.

(Pediatrician, Sofia)

While this construction of the vaccine as preventing cancer, might increase uncertainty about susceptibility to cancer for the population, on the other hand it serves to reduce uncertainty about whether to administer it to one's children (i.e. if it protects from cancer); as well as the discomfort and complexity of needing to bring in discussions of sexuality of pre-teen girls (Todorova, et al., 2012a).

When the sexual nature of the transmission is brought forth, it creates additional concerns regarding sexual behavior particularly of teenage girls. Interestingly, the sexual nature of the phenomenon has been picked up mainly by conservative and religious parents' groups in their fear of the vaccine's role in sexual dis-inhibition and loss of parental rights to choose. For example, vaccination has met with emotional protest from parents, and conservative and religious organizations in the US, that worry about its potential to undermine abstinence programs and lead to 'sexual dis-inhibition' of girls (Casper & Carpenter, 2008; Charo, 2007). Social conservative groups in the US have called it the "promiscuity vaccine" and thus contributed to the controversy surrounding it.

In contrast, the meanings of the vaccine as sexually dis-inhibiting were not evident in the Bulgarian or Romanian context in the study which we conducted. Rather than being worried about promiscuity, Romanian mothers were worried about the risk that the vaccine might cause infertility. As a matter of fact, the risk of infertility is seen as worse than the risk of cancer - since infertility "destroys your femininity" and "makes you not be a woman anymore" (Baban, et al., 2012).

In our previous work on meanings of cervical cancer prevention, cervical cancer was moralized and women were often blamed (including self-blamed) for contracting cancer because

of assumed promiscuous sexual behavior (Todorova, Baban, Alexandrova-Karamanova, & Bradley, 2009; Todorova, Baban, Balabanova, Panayotova, & Bradley, 2006). Yet, the vaccine, which clearly targets a sexually transmitted virus, did not evoke such constructions, which might be explained with the fact that the vaccine is relevant to pre-teen adolescent girls, before becoming sexually active.

In summary, the behavior of vaccination or rejecting vaccination is constituted in the local meanings of gender, gendered roles and responsibilities, and sexuality, including femininity and masculinity.

### *Structure*

Attitudes and behaviors of vaccination are constituted in local health structures and policies, which determine access to the preventive technology. The vaccines were licensed quickly and programs for vaccination were established in many countries. They aim at high coverage in order to reduce disparities by making it available to all (i.e. school based) (Bonanni, et al., 2011), and possibly result in herd immunity. Universal vaccination was introduced in many countries of Europe in 2007 through different forms of delivery and financing (school based, on demand, opt in or opt out, free of charge, co-payment). It is estimated that there is now about 50% coverage of the age cohorts in most Western European countries (Bonanni, et al., 2011). In the US, mandatory vaccination legislation (for school requirement) has not passed in most states, and vaccination is through primary care. It was estimated that 32% of the cohort of girls have received the three required doses in the US in 2010, considered low compared to other vaccines (American Academy of Pediatrics, 2012). The highest coverage seems to be in Australia, which was the first country to introduce a national school based program which has

covered nearly 80% of the cohort with 3 doses by 2009 (Brotherton et al., 2011).

Some of the women we interviewed were celebrating the vaccine as an achievement in the protection from cancer (Todorova, et al., 2012b). Some had vaccinated themselves and others were seriously considering vaccinating their daughters. Particularly in Bulgaria, the vaccine is inaccessible due to its high price, and the vaccine can take on the meaning of a desired but inaccessible luxury. It was constructed as exclusionary, mainly because of its price, as well as because of its age restrictions. Women protested its inaccessibility and were angered by the potential high profits for the makers of the vaccine, some still saying that for their health and their children's, however they are willing to find a way to pay it. They protested the unfairness of the fact that some are privileged and can have access to information and to effective means of preventing cervical cancer, while others do not. Many questions were asked about the possibility for including the vaccine in the National strategy on prevention and thus in the coverage by the health insurance.

Not only does price directly relate to access to the vaccine, but the price of the vaccine is closely tied to meanings of vaccination and thus to the constitution of attitudes and behaviors through dis/trust. In Bulgaria the high price creates mistrust for the reasons of potential profits for the companies and providers. In Romania the free provision of the vaccine creates mistrust and suspicion, that the vaccine is of low quality, or it is being tested on the populations at the eastern borders of the EU (Baban, et al., 2012). In Bulgaria similar attitudes are emerging, constituted in the context of the new policy for reimbursement of the cost of the vaccine, due to take effect at the end of 2012.

When they say 'free' – in a way some people can feel like a guinea pig. Personally I would accept it, but I'll think 'So they are giving it to me for free, who knows how old it is

(44 year old woman, Bulgaria).

The price of the vaccine is interpreted in the relevant socio-economic and cultural context, for example a woman in Romania shares: "...in the present Romania it is not good either way. If somebody offers you something for free, you are skeptical. You ask yourself why? When you have to pay, you ask yourself why so expensive? But when you pay, you have the feeling you are paying for quality service. (A, 35 years old).

Vaccination attitudes are also constituted in the individual choice and responsibility discourses that are part of the context of CEE countries within healthcare reform. The media and most health promotion efforts focus on individual decision making and choice – of adolescents (girls) or with their mothers. As mentioned, policies in EU are geared toward school-based programs, since they ensure broader access and reduce disparities. They are accompanied by opt-in or opt-out clauses yet certainly bring up the question of parental rights to make the decision; and thus intensify the questions parents have about safety.

Providers in Bulgaria see mandating vaccination as “civilized”; and as a solution to “irresponsible” citizens; they also feel that it will increase access (Todorova, et al., 2012a). In Romania, some doctors felt that the fact that the vaccination campaign was not mandatory was a mistake (and this is why it failed). Such constructions illuminate Eastern Europe’s social comparison with the West, as well as the potential for discussions and implementation of such programs to create divisions and categories of people such as responsible/ irresponsible citizens.

In Bulgaria, parental insistence on choice is tied to their mistrust and suspicions described above. Parents want to be able to choose since they mistrust the vaccine and other medications as low quality, beyond expiration date; the belief that they are imported to the East, when the West rejects them; the health professionals who distribute them are seen as irresponsible (or in

some cases, as having financial gain). These perceptions can be connected to historical context of obligatory health prevention or health monitoring programs.

In Bulgaria, the attitudes toward the vaccine are additionally shaped by local political interests and debates. In September 2012, the proposed *National Program for Primary Prevention of Cervical Cancer* was approved in Parliament. This means that 1 mil euro will be allocated to the National Health Insurance Fund (NHIF) for covering the vaccine. However, ever since the introduction of the bill, as well as after its approval, attacks have been directed toward the members of Parliament who authored it. The attacks claimed that those who introduced the bill, due to their connections with the NHIF, will benefit by diverting these funds for personal gain. After the approval of the National Program, anti-vaccine campaigns were re-ignited and were visible in social media, and have intensified public distrust of the vaccine.

In Romania, current attitudes toward the vaccine are constituted within the recent experience with the vaccination program and vaccination campaign. According to the mothers, the failure of the campaign can be explained in terms of poor organization and erroneous underlying assumptions. More specifically, some mothers argue that officials tried to endorse vaccine acceptance on grounds of gratuity, without providing sufficient information about vaccine properties. Some participants perceived this approach as deeply offensive and disrespectful. Consequently, vaccine rejection was seen as a justified decision if they were to preserve their dignity and pride. Notably, this “faulty campaign” was considered to be representative of “typical of how the Romanian system works”, as respondents projected their dissatisfaction towards the Romanian medical system in general to the vaccine (Baban, et al., 2012).

## Conclusions

New pharmaceuticals including vaccines are transported and transplanted into different contexts and elicit multiple personal and cultural meanings and discourses. The HPV vaccine is new, but observing how it enters societies “illuminates the tensions simmering in societies”. It can illuminate existing inequalities and divisions, as well as create new ones. In its travel to Eastern Europe, The HPV vaccine also brings forth relevant historical legacies around fear, mistrust, blame and responsibility, as well as specifics of current health system changes. It also shows how Eastern Europe sees itself as situated in comparison with the West.

People’s suspicions are not necessarily brought about by having a deficit of information. Negative attitudes toward the vaccine in Bulgaria and Romania rest on a mistrust of the healthcare system and multiple actors connected to healthcare provision, formed through decades of history – suspicion is directed toward governmental programs, pharmaceutical companies and in some cases individual providers. Women transferred to the vaccine their overall mistrust of the healthcare system, as well as their experience of different dimensions of inequalities and privilege. Healthcare (and thus the vaccine) is seen as poor compared to the West, as well as compared to what privileged individuals in Bulgaria can access; thus the HPV vaccine brings into relief existing disparities in prevention. The Bulgarian context is characterized by avoidance of the health care system (Avramova, et al., 2005), at the same time however, intersecting with positive notions of science and technology (Boyadjieva, Tchalakov, & Petkova, 1994). In Romania the attitudes toward the vaccine are embedded in a long previous history of repressive reproductive and sexual behavior monitoring and suppression of reproductive rights (Baban, 1999).

The socialist and post-socialist dynamics in the region construct a particular relation of

the public, health professionals and manufactures to new preventive technologies. The dismantling of the universal health system has brought forth new relations. A fundamental and generalized change of locus of responsibility for one's health – from collective responsibility resting with the State, to one focused for the most part on individual responsibility is observed. In this shifting situation we observe a coexistence of liberal notions of health care with both a nostalgic longing for the obligatory and centrally organized systems of prevention (Rivkin-Fish 2005; Todorova et al. 2006); as well as mistrust about potentially mandatory and coercive programs.

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