Providers’ constructions of the role of women in cervical cancer screening in Bulgaria and Romania

Irina L.G. Todorovaa,* Adriana Babanb, Dina Balabanovac, Yulia Panayotovaa, Janet Bradleyd

aHealth Psychology Research Center, Sofia, Bulgaria
bDepartment of Psychology, Babes-Bolyai University, Cluj-Napoca, Romania
cThe London School of Hygiene and Tropical Medicine, UK
dEngenderHealth, USA

Abstract

The social and institutional context of health-care reform in Eastern Europe has important implications for cervical cancer screening and prevention. The incidence and mortality from cervical cancer in Bulgaria and Romania have risen, which is in sharp contrast to the steady decline in most other countries in Europe during the last 2 decades. To analyze these dynamics we conducted a multi-component study of health systems and psychosocial aspects of cervical cancer screening in Bulgaria and Romania. Following the disappearance of organized preventive programs, the initiative for cervical cancer screening has shifted to providers and clients and depends on the way they perceive their responsibility and interpret their own and each other’s roles in prevention. We focus on how providers construct women and their role in prevention of cervical cancer through their accounts. The analysis identified several discourses and themes in providers’ constructions of women’s responsibility for prevention of disease. These include responsible women as ‘intelligent’ and ‘cultured’; non-attenders as ‘irresponsible’ and ‘negligent’; women as needing monitoring and sanctioning; and women as ‘victims’ of health-care reform. We discuss the implications for health-care reform and health promotion.

© 2006 Elsevier Ltd. All rights reserved.

Keywords: Eastern Europe; Cervical cancer screening; Providers’ perspectives; Bulgaria; Romania

Introduction

Cervical cancer incidence and mortality in Bulgaria and Romania

The incidence and mortality rates due to cervical cancer have been declining significantly in most developed countries since the 1960s (Waggoner, 2003). In Eastern Europe, however, the current social and institutional dynamics have important implications for cervical cancer epidemiology and prevention (Balabanova & McKee, 2002; Kouvakasov,
and Todorova, Tragakes, & Hristova, 2003), and have led to increased morbidity and mortality from the disease.

With a standardized mortality rate of 11.02 per 100,000 in the year 2000, cervical cancer was the second highest cause of cancer death in Romanian women, after breast cancer, and the first cause of death by cancer for the 25–44 age group (Nicula, 2002). 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 European Union countries (Dobrossy, 2002; WHO, 2005). Furthermore, rates have been increasing, with death rates 15% higher in 2000 than in 1990. According to WHO, cervical cancer mortality rates in Romania are approximately 2–2.7 times higher than in most other Eastern and Central European countries (GLOBOCAN, 2002; WHO, 1999) (Table 1).

In Bulgaria, cervical cancer is the third most common cancer in women (7.7%), after breast (24.6%), and skin cancers (9.8%) (Danon, Valerianova, & Ivanova, 2004). The incidence of cervical cancer in Bulgaria has been on the rise during the past 2 decades (Kostova & Zlatkov, 2000; Kostova, Zlatkov, & Danon, 1998), rising from 14.6 per 100,000 in 1980 to 27.2 in 2002. This has been paralleled by a significant increase in mortality rates. In Bulgaria, mortality from cervical cancer has nearly doubled from 1980 to 2002, increasing from 3.98 per 100,000 to 7.45 per 100,000, and is currently three times the European Union (EU) rate (WHO, 2001) (Table 1).

This continued rise of cervical cancer mortality in Bulgaria and Romania is in sharp contrast to the more or less steady decline of mortality rates in Western countries during the past 2 decades. It also contrasts with the situation in these two countries during the 1960s and 1970s, when rates were either stable or declining. The current situation can be explained primarily by the disorganization in cervical screening in Bulgaria and Romania (Levi, Lucchini, Negri, Franceschi, & la Vecchia, 2000). Socioeconomic factors have also begun to play a more obvious role. Affordability of the smear test, which was not a problem during the time of socialized medicine, has now become an important issue through what some have termed the “commodification of the cervix” (McKie, 1995). Power relations have also become implicated in different ways, for example, in Bulgaria, where general practitioners are closely monitored and are restricted in their ability to make professional decisions. The general practitioners are accountable to the National Health Insurance Fund (NHIF) through the allocation of a limited number of referrals to specialists, including the gynecologists, who are responsible for screening. At the same time, it is the general practitioners who hold the power to decide how to distribute these limited referrals, decisions that are based on medical and non-medical criteria, such as on the basis of first come–first serve, age, connections and others.

Since institutionally organized preventive programs do not currently exist, regulations are constantly in flux, and the practice of screening is confused, discourses encouraging individuals to take greater responsibility for their own health are coming to the foreground. Discourses on who should take the initiative for cervical cancer screening have shifted responsibility from the system, to individual providers and to women themselves. Thus, screening behavior is shaped by the way in which providers and clients interpret their own and each other’s roles in prevention. In order to reach constructive change, it is crucial to learn how information on prevention is understood and interpreted by both professionals and clients, and how this knowledge is translated into lived experience in practice and daily life. Disparities between the perceptions of the population served (women in our case) and those who provide health services, can lead to poor or minimal effects on screening behavior. Cultural and community factors can also enhance or attenuate the prevention intervention’s effect.

The transitional situation in Eastern Europe offers a unique context in which to study available

Table 1

<table>
<thead>
<tr>
<th>Country</th>
<th>Mortality rates (per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Romania</td>
<td>13.0</td>
</tr>
<tr>
<td>Serbia &amp; Montenegro</td>
<td>10.1</td>
</tr>
<tr>
<td>Albania</td>
<td>9.8</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>8.0</td>
</tr>
<tr>
<td>Poland</td>
<td>7.8</td>
</tr>
<tr>
<td>Moldavia</td>
<td>7.8</td>
</tr>
<tr>
<td>Hungary</td>
<td>6.7</td>
</tr>
<tr>
<td>Russian Federation</td>
<td>6.5</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>6.2</td>
</tr>
<tr>
<td>Ukraine</td>
<td>6.1</td>
</tr>
<tr>
<td>Slovakia</td>
<td>6.1</td>
</tr>
<tr>
<td>Slovenia</td>
<td>4.7</td>
</tr>
</tbody>
</table>

social discourses on disease prevention, and cervical screening in particular. The on-going health-care reform in Bulgaria and Romania creates an ideal situation for studying how current discourses of the benefits of a more pluralistic and liberalized health-care system intersect with nostalgic ones, longing for the centralized and mandatory nature of previous systems of prevention.

Tensions in the interpretation of cervical screening

Cervical cancer, widely recognized as caused by certain types of the Human Papilloma Virus (HPV), is the only type of cancer for which wide-scale systematic screening programs have been developed, and they are mostly based on the Papanicolaou (PAP) smear. In countries where screening programs have been available since as early as 1950–1960 (such as Canada, the USA, the United Kingdom, and Northern European countries), cervical cancer rates have fallen to low levels (Levi et al., 2000). Many epidemiological studies have also illustrated the cost effectiveness of mass screening programs (Laara, Day, & Hakama, 1987). Countries such as Bulgaria and Romania, where screening coverage has fallen and led to dramatic increases in incidence and mortality within a short period of 10–15 years, provide evidence of the importance of organized and wide-scale screening in preserving health at the population level.

With coverage a key issue, much of the research in health psychology has sought to promote effective psychological interventions for increasing screening uptake, and to identify and eliminate psychological barriers to this behavior (Aiken, Gerend, & Jackson, 2001; Bish, Sutton, & Golombok, 2000). Other approaches have stressed the structural barriers and unavailability of resources, limiting women’s access to information and services (Population Reference Bureau, 2004). All of these approaches have assumed the necessity and health benefits of regular screening of a large proportion of the population, and thus cervical cancer screening has rarely been placed under critical analysis. However, work has also drawn attention to some negative aspects or proposed alternative and parallel readings of the meanings of cervical cancer screening. An Editorial published in the British Medical Journal, (Austoker, 1999) discusses the complexities of cervical screening and states: “The detrimental side effects of screening include anxiety, false alarms, false reassurance, unnecessary biopsies, over-diagnosis, and over-treatment” (p. 322). The unfavorable aspects of screening can also include ambiguities in interpretation, psychological consequences of inconclusive smears, creating a sense of “embodied risk”, blaming of non-attenders, and others (French, Maissi, & Matreau, 2004; Holland & Stewart, 2005; Howson, 2001; Maissi et al., 2005; McKie, 1995).

This paper is situated in tension between an awareness of the health benefits of screening on the one hand, and some of its alternative meanings on the other hand, particularly the way in which it can embody power relations and lead to blaming and categorization of women. We ask if there are negative dimensions of current discourses and practices of cervical cancer screening in Eastern Europe, while at the same time emphasize the importance of making screening available and affordable for all women. In other words, to quote Judith Bush, we explore whether “the perceived need for regulation and surveillance of women’s bodies can be challenged without threatening women’s health and well-being” (Bush, 2000) (p 442).

Methods

The data we present are part of a larger International Study “Psychosocial and Health Systems Dimensions of Cervical Cancer Screening in Bulgaria and Romania”, conducted in collaboration between the Health Psychology Research Center in Sofia, Bulgaria; the Department of Psychology at the Babes-Bolyai University in Cluj-Napoca, Romania; and EngenderHealth, USA. The project involved a comprehensive study of health-care providers, patients, and key informants in the health-care systems of the two countries. The objective was to describe the current systems for cervical smear testing, socioeconomic screening disparities, attitudes, and risk perception of women regarding cervical cancer screening, as well as the key health-care system elements needed in Bulgaria and Romania for effective implementation of cervical cancer control.

Whilst most studies of health-seeking behavior or access to preventive services have focused on the perspective of users and analysis of health systems, it is also important to solicit the views of front-line providers, who have the power to influence patterns of access and utilization (Sarkadi, Widmark, Tornberg, & Tishelman, 2004). This approach is particularly
relevant in the circumstances of highly medicalized, hierarchical and traditionally paternalistic health-care systems in Bulgaria and Romania, where women have little power and voice to influence the services available to them. While studying women’s perspectives will uncover a range of existing barriers to obtaining a smear test (Baban, Balazs, & Szentagotai, 2005; Todorova & Kotzeva, 2004), a detailed understanding of provider perspectives will provide clues to what policy strategies are needed to motivate them to promote cervical cancer screening and discuss it in more detail with the women who visit them. Providers’ opinions in this project are discussed in detail elsewhere (Babes-Bolyai University & EngenderHealth, 2005; Health Psychology Research Center & EngenderHealth, 2005). In this paper we focus specifically on how providers draw on intersecting social and professional discourses in the process of constructing the role of women in the prevention of cervical cancer.

The current paper is based on semi-structured interviews with 50 health-care providers in each country, including general practitioners, gynecologists and cytologists. In Bulgaria the interviews took place in the cities of Sofia, Pleven, Kardzali and Varna. In Romania, health-care providers from nine major cities (Bucharest, Cluj, Sibiu, Targu Mures, Satu-Mare, Oradea, Fagaras, Bistrita, Zalau) were interviewed. The sample was purposive and aimed to give a heterogeneous representation by gender, training, length of work experience (including people who worked before 1989), and positions at different levels of the system (GP practice, polyclinic, general or maternity hospital, oncological facility). The interviews were conducted in stages and in accordance with the principles of Grounded Theory—findings from the first few interviews informed the selection of the rest of the sample, for example, identifying the need to include cytologists in the sample. The interviews were based on a semi-structured questionnaire and lasted about 1 hour.

In Bulgaria the sample of health-care providers consisted of 28 gynecologists, 16 general practitioners, five cytologists, two nurses and one gynecological surgeon. Of these 52 providers, 29 were women and 23 were men. In Romania the group of 50 health-care providers included 23 general practitioners, 11 gynecologists, six cytologists, five family planning doctors, four oncologists, and one epidemiologist. Of these, 27 were women and 23 were men.

The interviews aimed to elicit providers’ perspectives on multiple aspects of cervical cancer and screening, including practices, procedures and financing, following the same semi-structured protocol in each country. There were only a few questions that directly asked providers about what they felt should be the role of women in prevention, so to a great extent their constructions of women became apparent indirectly through their answers to other questions throughout the interview. These include questions that explored roles and responsibilities in cervical cancer screening; opinions about individual or system-level barriers to screening; adherence by women; and strategies for promoting attendance.

The interviews were transcribed verbatim and the analysis was informed by the method of constructivist grounded theory (Charmaz, 1990, 1995) with an explicit social constructionist orientation, acknowledging that both the interviewees’ and researchers’ ideas shape the understanding of the phenomenon under study. We proceeded through an initial coding for themes, which were subsequently organized into broader categories, referring to providers’ assumptions and images of women, as well as to the possible consequences of these constructions for the practice of cervical screening or prevention more generally.

**Results**

**Women as irresponsible: “They hide their heads in the sand”**

A recurring theme in the providers’ accounts is the construction of women as having an inherent lack of responsibility that leads them to avoid preventive exams in general and cervical cancer screening in particular. This is framed in terms of **deficits**: non-users of the screening are perceived as “unintelligent”, having low “health culture” and being “unreasonable” and users are thus juxtaposed as being the opposite.

In individual cases, particularly strong words are used, describing non-users as “ignorant”, “primitive”, “careless” or having a “primitive consciousness”. Sometimes explanations for low attendance are given based on women’s embarrassment and fear of the gynecological exam, as well as cultural and religious understandings that might limit gynecological visits, but more often it is the explanation invoking “irresponsibility” and lack of understanding of prevention that dominates.
If a woman is more intelligent, she can find information herself. As do most of the patients I work with. If the woman is... fortunately I don’t have any of those patients—but if she is below a certain level of intelligence, it doesn’t matter how much you explain to her.... (man, GP, Bulgaria)

Very few women request the Pap test on their own initiative; their low health cultural level prevents them from taking action in this respect. They think that they need screening only if they have symptoms or if cancer runs in their families. They tend to respond to health problems only when there is an emergency. This attitude means higher costs for them and for society, but they don’t take this into consideration. (man, gynecologist, Romania)

A woman is willing to pay probably double of what a Pap test costs to get her hair done. But this is what Romanian women are like: as long as they don’t have any health problems, they are more concerned about the way they look on the outside than about what goes on inside of their body. (man, gynecologist, Romania)

A moralistic construction also becomes evident in different forms around the theme of “responsibility” and its absence, for example, when providers insist that it is women’s duty to be screened since they have a responsibility to tax-payers or to their children.

So if this woman (who has not been diagnosed at an early stage) comes in for surgery (later on), she’ll be opened up, then closed, radiation therapy starts, chemotherapy, staying in the hospital, things like that. So, instead of one operation, which costs 200–300 leva for the NHIF, it will cost the taxpayer tens of thousands. Who will pay for her recklessness? (man, gynecologist, Bulgaria)

Romanian women are focused only on their children’s health. They are not aware of the importance of taking care of their bodies and paying attention to their own health. They can’t understand that if you take good care of yourself, you could take care better of those depending on you. (man, gynecologist, Romania)

There is a common perception among providers that women do not understand the importance of preventive medical check-ups, because they are not properly educated to assume responsibility for their own health. In the meantime, however, many do not consider that their “job description” includes communicating public health messages or providing basic health information, which is seen beyond the scope of their role. According to some health providers, women should be more responsible when it comes to their own health, and consequently be more proactive in asking for regular medical check-ups:

We are clinicians, and by definition a clinician deals with medical problems, not with education and prevention. (man, gynecologist, Romania)

Interestingly, a gendered discourse is not obvious here; in other words, it is not “women” in particular who are constructed as irresponsible. Some providers explicitly state that “it doesn’t matter whether it is a man or a woman—they all avoid prevention”. In other cases this absence of gender-specificity is seen in the language that they use: providers use the term “people” or the masculine form (which is used as the more universal form, encompassing both men and women) even when they are speaking of cervical cancer screening.

Quite pervasive is a construction based on “national character”, or an even broader “Balkan character”. Avoidance of necessary health-care use is explained through an irresponsibility and irrationality that is perceived to be intrinsic to the people of Bulgaria and Romania and, more generally the Balkans. ...irresponsibility...the tragedy...I’m repeating myself, the tragedy is in the way the Balkan person thinks. (man, gynecologist, Bulgaria)

This is the typical Romanian mentality, of putting off for tomorrow something that you could do today. Romanians do not think of the future if they are OK in the present. They only do this when confronted with a problem. (woman, gynecologist, Romania)

This explanation based on national character can be interpreted at times as something that is inherent to the people of the region, while at other times is seen as a result of the ideologies of the communist system, or of the attitudes toward health care created by the socialized model of health care. The idea is that socialized medicine, with health care provided free at the point of use, has created irresponsible and passive people, who are used to being taken care of by the powerful State and
uninformed about what to do when the State is no longer regulating their bodies.

So the tragedy is that for decades it has been instilled in peoples’ heads in the Balkans that healthcare is free. (man, gynecologist, Bulgaria)

That’s the Balkan person’s problem. Everyone is waiting for something to come from above—for the State to give. The State can give, but one’s ignorance, that I think, is not an excuse. (man, gynecologist, Bulgaria)

...in other words, the goal of all this is to create an interest and personal responsibility. If you don’t hit the Balkan person in his pocket, there is no responsibility. (man, gynecologist, Bulgaria)

This “Balkan” explanation, and the notion of the need for compulsion, fit with the idea that people/women need to be watched and penalized in order to follow prescriptions for prevention.

**Women as needing surveillance: “It’s the women with, let’s say, more uninhibited behaviors”**

The construction of women as needing surveillance is most obvious in the statements that connect cervical cancer incidence with permissive sexual behavior. While there are some providers who state that it is irresponsible and stigmatizing to make an association between sexual behavior and cervical cancer onset (stressing that having even one partner can result in transmission of the virus), many more do insist on this association. The expression most often used by these providers is that women with “indiscriminate sexual partners”, “promiscuous sexual women” are more likely to develop cervical cancer. While a gendered discourse was not relevant for the construction of “irresponsibility”, it was very obvious in the construction of “promiscuity”, where only women’s sexual behaviors were blamed.

Everyone who is sexually active is exposed to being infected with HPV. However, when a woman likes “to fly from flower to flower”, it would be better for her to know what risk she exposes herself to and to ask for regular Pap tests. (man, gynecologist, Romania)

It’s the women with risky behavior, let’s call it social behavior, promiscuity, with multiple partners, or let’s say it directly—prostitutes and so on (who are at risk). (man, gynecologist, Bulgaria)

We can ask “is there a genetic component to this disease?”, since it is often seen in mothers and daughters, who both get cervical cancer. Most probably they have inherited the same weakness of the immune system, or probably also a desire for promiscuous behavior (laughs). (man, cytologist, Bulgaria)

Not surprisingly, this leads to identifying young women as being at greater risk for cervical cancer and focusing the clinical gaze on them. What is surprising is the extent to which the providers share the idea that cervical cancer among the young has increased dramatically in the last few years.¹ This construction is of concern not only because of its blaming and regulatory nature, but also because it diverts attention away from those older age groups who are at greater risk for cervical cancer to focus the regulatory mechanisms on women whose sexual behavior “needs” to be under scrutiny.

In the schools girls are starting sexual activity at age 12 and by the end of secondary education they are all sexually active, so this age group absolutely has to be included (in screening), since the virus is much more dangerous in young people. The younger the epithelium, the more susceptible it is to the viral infection. (man, cytologist, Bulgaria)

The focus on disease monitoring links to what we can interpret as over-medicalization of screening observed for both countries. This is exemplified in the insistence that cervical cancer screening needs to be conducted much more frequently than both national and international guidelines currently recommend. Most providers insist that screening has to be done “at least once per year” and many others state that it is “widely known” that it has to be done every 6 months.

There are women, especially in the villages, who haven’t been for a gynecological check-up, in for example 30 years. So they say ‘Doctor, I haven’t been to the gynecologist since I had my son, 30 years ago”. But every self-respecting woman should see the gynecologist of her own accord every 6 months. (man, gynecologist, Bulgaria)

¹Though undoubtedly providers are noticing this change in their own practice, it might be a result of the total increase in cervical cancer cases, rather than particularly for younger women. According to the epidemiological data for Bulgaria, the relative increase of CC incidence is lower for younger women.
The test should be a part of the obligatory health program of any woman. Women should be tested twice a year, particularly if they belong to a certain age group or an enhanced risk group. (man, GP, Romania)

Though providers do not explicitly propose a different frequency of screening for young women, the twice-yearly screening is most often invoked when referring to younger women. Not only age, but also socioeconomic disparities come into play, since because of the rationing of care by the NHIF, only those (usually younger) women who can afford private visits can actually conduct the recommended though unnecessary, frequent screenings.

Women as needing to be penalized: “It won’t work without force”

It is striking how often most providers interviewed recommend penalties as a means of controlling non-attenders. Many health providers conceptualize screening as something that should be imposed on women from above. Women are perceived as not being mature enough to make active choices and this creates an ambiguity between the personal responsibility and surveillance discourses put forward by the providers. The issue of compulsion and penalty is raised by almost half of the Romanian and Bulgarian providers interviewed, proposing sanctions for people refusing to attend general preventive exams. Though recommendations for introducing sanctions are combined with other suggestions, such as increasing health promotion, restructuring of the health-care pathways, etc., punitive measures are particularly favored, with the belief that the end justifies the means.

I always encourage women to keep up with regular medical exams, and among them Pap smears, but after 23 years of practice I have reached the conclusion that without obliging them through some means, women are not likely to do what is right. (woman, GP, Romania)

So the fact that people don’t go and they are not interested—well they should pay for that, even with their heads… The taxpayer is not supposed to be paying for her reckless foolishness. (man, gynecologist, Bulgaria)

The extent to which most providers believe that such measures are the norm in the West is also notable. Many of them state that “this is the way it is in other countries”, and Bulgaria and Romania need to follow that model. Several forms of penalizing measures are mentioned: exclusion from insurance, fines, increases of the monthly insurance premiums, or the requirement to pay for medical treatment if proven that the condition could have been avoided by preventive medical examinations. The most punitive are measures which would deprive women who have not had smears from treatment coverage should they develop cervical cancer.

I know that in other countries women that don’t show up for screening cannot benefit from certain facilities offered by insurance companies. If Romanians were educated the same way, I bet they would take better care of their health. (man, gynecologist, Romania)

There is no way to force her. The only way to do that, which is accepted—there are many colleagues who support this and many countries in which it is practiced—if the woman gets cervical cancer and hasn’t been for a smear, she pays for her treatment on her own, because treating cancer is expensive. Difficult, expensive and long. It costs the State and the whole society a lot. (woman, gynecologist, Bulgaria)

According to a quarter of the respondents in Romania, compulsory Pap screening when being hired for a new job would be another way of reducing cervical cancer mortality and morbidity. Some of them mention, however, that such a testing method could involve resistance as it would “bring up unpleasant memories from the compulsory gynecological testing period of Ceausescu, especially for women over 40 years of age” (woman, gynecologist, Romania).

A few health providers suggest the idea of having certain incentives introduced, such as financial bonuses, and the reduction of health insurance taxes for women attending regular medical check-ups. Though rare and muted, there are also voices which insist that whether a woman attends for a smear or not, is a matter of choice and informed consent, a theme entwined with the following more caring one.

Women as victims of health-care reform: “The health reform has completely neglected women”

While many providers in Bulgaria and Romania use the discourse of blaming women for their
“irresponsible” attitude toward health, others use negative evaluations of the transitional health-care system in the two countries to construct their explanations, identifying it as the main barrier to accessing the health prevention services women need. The discourses constructing women as the victim and then blaming the victim are often entwined in the account of the same respondent.

The descriptions of the current efforts toward health-care reform very often use comparisons with the health-care system before 1989. The comparison, which is also posed by younger providers, usually favors the previous system, in the sense that “it was better before”, though some providers also feel the need to make it clear that “…not that I’m in favor of communism, but…”. They point out limitations of the previous system, for example, some dislike the mandatory nature of the program, the pressure to achieve high screening rates, leading to a high number of unnecessary repeat smears. However, many feel that those programs were critical for protecting women from cancer and many note the pain they felt at the destruction of a workable system to which they had dedicated their lives. Some give the example of the organization of screening in the past as a model of best practice.

So we had delegations here, who visited our dispensaries, who saw our cytological laboratories and our Department “Prevention and Early Detection” and were amazed. This system for oncological care, which we had, was a terrific one. Now in Denmark they are trying to create a system like ours, which we lost, and they’re having a hard time creating it, even in such advanced countries, since it is not at all easy. (woman, gynecologist, Sofia, Bulgaria)

Years ago we used to have screening programs that were more efficient in my opinion. Women working in factories were requested to come for oncological screening. It is true that screening programs were sometimes used as a means for detecting unwanted pregnancies. The pregnancy was officially recorded, and the woman could do nothing to get rid of it anymore, in case she did not want it.² But cervical cancer detection was an aim as well. (man, gynecologist, Romania)

Throughout this theme, women are constructed as vulnerable, neglected and abandoned by the State. Providers see women as needing protection and support, as needing “someone to lend them a hand”. In some cases, providers note that it is the State that should lend this support, both financially and structurally, while in others, they position themselves as those who can be the protectors. They are particularly concerned about women’s inability to pay for screening in the private sector, considering the limited free referrals that are funded by the Health Insurance Fund.

For the past 10 years, it’s not a secret, there are no resources for prevention. No one is providing resources. How will a woman come to me when she knows that I have to treat her, take a smear, and if the GP does not allow it (give referral) where can she find the money to pay? (woman, gynecologist, Bulgaria)

On the one hand, our goal is to promote screening among the female population, while on the other hand we are forced to be “reserved” in informing and mobilizing women since we would not be able to cover the needs if all women in the target population start asking for the test. (man, oncologist, Romania)

Other providers suggest that the main factor hindering women seeking care is the socioeconomic reality of life that imposes other priorities on women:

In our country, you know what things are like: the vast majority of women have other, more vital, daily survival tasks on their minds, and health is left to last. Prevention is given no attention whatsoever, and women go to the doctor only when they have a problem. But you can’t do prevention this way. Women should be educated that it is easier to prevent than to treat. (woman, gynecologist, Romania)

The theme of women as victims of reform has multiple nuances in its interpretation. On the one hand it constructs the notion of passive women, needing the care and protection of the State and the gynecologists. Women are seen as victims of the chaotic and disorienting health system transformation, which has left them in limbo, without support and without the information they need to take action. Also, for many providers the attractiveness of the previous system is contained precisely in its ability to regulate, mandate and thus attain wide coverage. At the same time, this theme captures the concern for the well-being of women; providers see

²Referring to the illegality of abortion in pre-1989 Romania.
rapidly increasing numbers of invasive cancer cases and are frustrated by their own helplessness to reverse this trend. In the emphatic words of one female gynecologist in Bulgaria, “the reform has been genocide… genocide against our people”. This theme illustrates very explicitly providers’ sense of moral obligation towards preserving women’s health, but also the sense that their hands are tied by many structural constraints and procedures.

The role of prevention is very important and for the past 10 years we’ve had no prevention. If we continue in this way, we will not have any healthy and living women. We don’t even know the word prevention—“what is that?”—we’re asking ourselves. (man, gynecologist, Bulgaria)

Discussion

We have illustrated how providers construct images of women and women’s roles in the prevention of cervical cancer, drawing on available social and professional discourses. As the results highlight, the constructions of women participating in cervical screening are shaped by a number of complex, and often contradictory discourses. We identified four major discourses in the medical representations of women’s responsibility in cervical screening: that of blame, that of medical authority having a monitoring function, a punitive discourse and the discourse of victimization entwined with care. All the constructions can function to jeopardize women’s agency in their encounters with the health system and health-care providers.

Most of the themes identified are surprisingly common to both the Bulgarian and Romanian contexts. Additionally, based on our analysis of the frequency of appearance of these themes, we can state that in both countries men providers tended to evoke the discourse of blame, of surveillance and of punitive actions more frequently than women providers; while women providers tended to talk about women as victims of medical reform more frequently than men.

Several ambiguities emerge in these accounts. The first emphasizes the importance of preventive exams, while having to stress the priority given to the truly sick in their daily activities. This ambiguity has been apparent for decades in medical discourse, in terms of highlighting the importance of prevention yet offering limited institutional or financial resources, which serves to marginalize preventive efforts. Currently, it is reinforced by the existing referral system, which sets limits to care and thus prioritizes acute care.

The second ambiguity is generated by the transitional social context in Bulgaria and Romania, in which reminiscences of the old system intermingle with new elements modeled on Western health-care systems. Studies have shown that among populations in Eastern Europe there is a strong perception that responsibility for health should be collective, and promoted through state institutions (Balabanova & McKee, 2004). This preference for collective public service provision is manifested more strongly in Bulgaria and Romania than in other former socialist countries (Rose & Makkai, 1993). In the new shifting situation we observe a coexistence of liberal notions of health care with a nostalgic longing for the obligatory and centrally organized systems of prevention. In other words, the paternalistic and authoritative discourse about women coexists with that emphasizing individual responsibility and self-agency in disease prevention. These mixed messages (even if not explicit), certainly contribute to women’s confusion regarding their role in taking on the protection and promotion of their own health. This also creates a setting which can foster the emergence of unfavorable aspects of cervical screening and ultimately threaten human rights.

The social and moral dimensions of participation in screening have been exemplified in the literature. Quoting documentation from the Council of Europe, Holland and Stewart (2005) present the possible consequences of screening, including “stigmatization and/or discrimination of (non)-participants”, as well as “social pressure to participate in screening and undergo the intended treatment/intervention” (p. 10). Howson (1999) has also illustrated how the emphasis on greater uptake of screening can lead to categorizing women into compliant and non-compliant, normal or deviant, or even into moral or immoral. Authors working from a Foucauldian perspective have argued that the imperative to participate can concurrently be a form of surveillance of women’s sexuality and sexual behavior (McKie, 1995), one that has become fully normalized so that the way it is practiced is not questioned (Bush, 2000). In the words of Howson (1999) cervical cancer prevention can exert “subtle degrees of moral control over individuals” (p. 402).

What we see from the analysis of providers’ accounts in Bulgaria and Romania is that there are
subtle, but also very explicit and formalized ways of controlling behavior and mandating screening that are being introduced. There were some providers who see sanctions for non-attendance as contradicting informed consent and human rights, and propose that positive incentives would be more appropriate. However, most providers widely support mandating screening. It is of great concern that financial sanctions for non-compliance have now been legalized with the passing of the new Bulgarian Health Law in 2004 (Bulgarian Parliament, 2004). We believe these sanctions for failing to attend for prevention are contradictory to the principles of informed consent, which, are also firmly embedded in Bulgarian health legislation. Exactly what will be included in the “preventive exams” that will be covered by sanctions is not clear, but we can argue that such measures will be particularly discriminat- ing against women, since breast and cervical cancer screening have received much more attention compared to prostate cancer screening.

In Romania there still is an ongoing debate about the possibility of legalizing sanctions for non-compliance with the regulations concerning disease prevention and risk factors surveillance. The punitive discourse echoes similar ones from the former Romanian communist regime, which opened ways for “disciplining” women’s bodies and set restrictions to women’s right of self-determination by defining women primarily in terms of their reproductive capacity (Kligman, 1998). Providers from both countries employed rhetoric consistent with the norms of an autocratic health system, where the health provider is a dominating figure who evaluates the unaware, uneducated and irresponsible women. Hence, through sanctions proposed for women who do not adhere to medical advice for cervical screening are constructed as deviant, and therefore should be coerced to act in line with medical advice. A penalty is seen as the obvious solution for normalizing the situation and bringing benefits to the unaware, uneducated and irresponsible women. Hence, through sanctions proposed for women who do not assume a responsible role in health promotion, the medical system helps to legitimate the monitoring and penalizing of women.

Of concern is the way in which mandating screening and punitive approaches to screening are widely presented as being the norm in “Western countries” and as progressive, since they will align Bulgaria and Romania with what is practiced in Europe. In fact, current policy in Europe takes the opposite direction. The Second Report of the UK National Screening Committee, when assessing the current situation (UK National Screening Committee, 2005), (p. 7) advocates for introducing a more balanced approach to promoting screening, in which clients are informed about the high health benefit for the population, but also of the fact that a small number of individual users could experience adverse effects and each individual should be offered adequate information in order to make a decision. The recommendations of the Council of the European Union for cancer screening (Council of the European Union, 2003) also stress that individuals should be able to decide whether or not to participate in screening programs. Though a high level of compliance is sought, it has to be based on “fully informed consent” (p. 36).

Most providers describe at length the barriers to screening created by the restructuring of the healthcare system, and express frustration at the consequences for women’s health. However, this discussion is entwined with an extensive blaming of women, who are seen as essentially irresponsible about their own health. Our analysis illustrates how compliance or non-compliance with screening can function to label and categorize women and encourage moral evaluations. This is further evident in the association which providers make between cervical cancer incidence and “promiscuous” sexual behavior. While the HPV is undoubtedly transmitted through sexual contact, it has a very high prevalence in both the male and female population. Thus, the absence of consideration of men’s presence in the sexual encounter and role in transmission is striking and underscores the gendered biases implicit in existing discourses of blame and responsibility. We can further hypothesize that as this association with “promiscuity” infuses the social discourse, it can function to create further barriers and avoidance of screening, because of the possible stigmatization of women with cervical cancer.

The construction of the avoidance of preventive behavior as a reflection of “Bulgarian character” “Romanian character”, or even broader “Balkan character” is a source of concern because of its determinism, since it can ultimately impede health promotion efforts. Even when this construction is perceived as not inherent but rather seen as shaped by decades of living under a paternalistic communist system, it nonetheless has the connotation of something difficult or impossible to change. Though most providers stress the importance of health
promotion, there is an ambiguity in the belief in the success of these efforts.

Providers’ focus on young women as particularly at risk for cervical cancer, if given unwarranted consideration, can function to divert attention away from those older age groups who are statistically at greater risk. Additionally, the insistence that screening needs to be conducted every 6 months is not cost effective, can place a significant burden on the Health Insurance Fund or on the women who are willing to pay in private practices, and also leads to extensive regulation of women’s behavior.

The conclusions from this analysis in terms of policy reform in Bulgaria and Romania are that structural and financial changes need to be made in order to assure that cervical screening is widely available and that all women have equal access to the procedures. Health promotion efforts need to underscore presenting balanced information, challenging the discourses that intrinsic personal and national characteristics are the main barriers to screening, as well as those of the need for multiple screenings throughout the year. Health promotion efforts also need to include information about HPV prevalence and transmission and the relational nature of sexual behavior, so as to destigmatize the disease and engage men in cervical cancer prevention. The study emphasizes the importance of informed consent in cervical cancer screening. Since the procedure is constructed as routine, its health benefits as clear and cost-benefit as significant, the issue of informed consent appears almost irrelevant to many providers. Many steps still need to be taken in both countries to assure the patient’s right to be informed, and to be empowered to make informed decisions.

Acknowledgments

We would like to thank the Bill & Melinda Gates Foundation, which funded the current study though EngenderHealth and the Alliance for Cervical Cancer Prevention. We are also very grateful to all the participants who shared their opinions with us.

References


