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CONFERENCE REPORT

EUROGIN 2007 Patient Education Conference: Sharing experiences and action in cervical cancer prevention – an overview

Part 2

Nearly 2400 people attended the annual EUROGIN Conference this year, held on October 4th–6th, 2007 in Monaco. The chairman of EUROGIN, Dr. Joseph Monsonego, opened the conference this year with the first ever Patient Education Conference. This one-day gathering of health specialists, academic experts, and representatives from governmental and non-governmental organizations provided an opportunity for knowledge exchange, consensus building and networking with the goal of improving communication between health professionals and the community at large, particularly women.

More than 30 invited speakers participated in the one-day agenda.

The goals of public health education are to increase the public awareness of diseases and their causes, clarify “at risk” personal behaviours within a culturally sensitive context, and motivate healthy people to participate in preventive programs.

The agenda of the First Patient Education Conference was designed to give a voice to stakeholders at several levels, starting with women affected by the disease, health care professionals, academic researchers, public health officials, the media, industries and advocacy groups from civil society and women’s associations.

A more detailed conference report is available at the web site of EUROGIN (www.eurogin.com). In addition, an evidence-based consensus report to guide medical professionals in their daily clinical management of patients, is published in this journal.

Testimonials of cervical cancer survivors

The Patient Education Conference started with testimonials from cervical cancer survivors, about their journey through both physical and emotional suffering, from diagnosis through treatment, cure and recovery. They reported that talking about cervical cancer can be embarrassing because of links with sexually transmitted infections, and femininity can become an issue. Women confronted with a cervical disease need objective, expert and accurate infor-

mation about their disease and treatment, and need to be listened to, and be supported with confidential medical advice. They learned that, fortunately, today several life-saving tools are available to prevent this cancer: vaccination, cytology screening tests, HPV tests. Women need to have a voice and take every opportunity to talk with simple words about HPV and cancer prevention. Personal testimonials represent one way of increasing awareness that cervical cancer is not a fatality, it can be detected early, treated, cured and effectively prevented.

Current knowledge of HPV and cervical cancer

Knowledge is essential for full participation of the public in the preventive measures offered by health professionals. However, the majority of the general public is still unaware of HPV infections, or the fact that cervical cancer has a viral aetiology. Hence, the first part of the education conference was aimed at reviewing recent data from published surveys on consumer knowledge about HPV, its associated diseases, screening options and vaccination. The speakers highlighted that the knowledge level of prevention options can be regarded as a predictor of acceptability of the prevention approaches.

Results of various surveys were presented. For instance, in the US, the awareness of cervical cancer and precursor diseases is high (95–100%) while knowledge of HPV as a cause of cervical cancer is known by 54–65% of young adult females responding to Internet based surveys. Skin-to-skin contact as a risk for contracting genital diseases, is known by 50% of young adult females (18–26 years old) and by 30% of young mothers (over 27 years old) responding to the surveys. Surveys comparing the knowledge of HPV, among women over 30 years old, in the US and Germany, showed that 65% of respondents had heard about HPV in the US, while only 15% reported the same in Germany. However, in-depth knowledge about the virus is still limited with 10–25% of US respondents reporting that they knew something about HPV, compared to 2–4% of respondents in Germany. Knowledge of the need for cervical cancer screening, even after vaccination, is high in both US (85–100%) and Germany (54–92%). Another survey reported that the public awareness of HPV in the UK is low, with 25% of the general public reporting that they have ‘heard of’ HPV, 10% agreeing with the statement ‘HPV is a cause of cervical cancer’, but only 3% could recall that HPV is a cause of cervical cancer. The surveys suggest

that education is the key to changes in preventive health care behaviour.

The complexity of the information related to HPV associated diseases makes it difficult to ensure that it is accessible and comprehensive to everyone, and this topic was extensively addressed by the speakers at this conference. The content of HPV information materials should consider what women want to know, and what is needed, to achieve appropriate responses to health outcomes. It was agreed by the discussants, that there is a need to communicate positive messages to minimize the shame, anxiety, stigmatization and fear of disclosure to partner, that often accompany a diagnosis of cervical disease. A recent study in the UK was reported, that evaluated the impact of seven key information points about HPV infection, which women find reassuring, on the cognitive, behavioural and emotional responses. The messages were tested on a sample of female students, in a randomized fashion, as compared to information on breast cancer and a control group. Interestingly, the implicit negative responses to cancer cues were markedly reduced in the group presented with the specific seven HPV information points, as compared to the two other types of information, reflecting a decrease in anxiety elicited by that HPV information. Moreover the acceptability quotes towards HPV vaccination increased by 20% after exposure to the specific HPV information. In addition, the proportions of women planning to attend screening after the three types of information increased by 15–20% after presentation of the specific HPV information, indicating a positive attitude towards participation in preventive programs, following exposure to this health information.

In summary, the speakers recommended that HPV information be evaluated on its impact on attitudes and behaviour related to preventive health care. Well-designed information can reduce fear of cancer, promote engagement with cancer preventive behaviours, facilitate informed decision making and informed choice, and ultimately contribute to reduce inequalities in cervical cancer incidence across the world.

Role of health care professionals, governmental and non-governmental organizations in patient education

The opportunity for comprehensive cervical cancer control is now at hand through the dual application of primary and secondary prevention tools, namely HPV vaccination and cervical cancer screening. HPV vaccination media campaigns have generated demand that calls for clear, non-biased, non-commercial public education, even in countries where vaccination is not yet available.

Round table discussions among health professionals at the conference addressed various educational issues. Health professionals often have the task of developing policy and advising political leaders; therefore, it is very important to inform them about HPV, associated diseases and preventive tools. In some countries, decreased cervical cancer incidence has been observed and documented after implementation of organized screening programs. Having similar results for vaccination would provide assurance that there would be a positive impact on disease burden locally. There

is a need to establish vaccination and monitoring programs in some countries, while other countries need to strengthen screening programs as well. The discussants added that male education programs should be considered whenever possible, because males play a vector-role in the spread of HPV related diseases. In this context, public health structures can play an important role in implementing education programs.

Ongoing efforts from public health agencies to fulfil the demand for better information to the public at large, were mentioned including, for example, the launching by WHO of the HPV Community of Practice, an on-line forum for health professionals to exchange information about patient education efforts globally. Further, the International Agency for Research on Cancer has created a series of educational materials about HPV and cervical cancer prevention available on their web site (www.iarc.fr). The European Union's public Health Programme has developed guidelines on the implementation of cervical cancer screening as a tool for cervical cancer control. The French National Cancer Institute, part of the Ministry of Health, is creating policy and coordinating stakeholders in four areas: prevention and screening, health quality control, research and public health information. The US National Cancer Institute is involved in laboratory based research, epidemiological or behavioural studies, while the US Centers for Disease Control and Prevention (CDC), functions by interfacing with the broader public health community and governmental agencies to coordinate the development of information for the public.

Similarly, a number of organizations have recently engaged in cervical cancer prevention activities. For instance, the conferences of EUROGIN and its sister organization, the Asian Oceania Organization on Genital Infection and Neoplasias (AOGIN), contribute towards communicating HPV messages in culturally sensitive and appropriate ways to professionals and the public; the European Cancer Leagues Association is actively advocating for effective and harmonized prevention programs at national level that should be implemented across Europe; the American Cancer Society (ACS) has communication and education programs targeted to various groups including medical professionals, public health officials, and the public with special focused outreach to underserved populations.

Women's organizations such as Women in Government, Balm in Gilead and Women Summit of Women, 1000 Femmes 1000 Vies, Jo's Trust have reported about their communication tools, and national and international health initiatives to increase public awareness about cervical cancer and HPV. Still, nearly half of the cervical cancer disease burden is among women in Asia, who in many instances do not have access to Internet, TV, radio, conferences, or other communication tools. Hence, very simple messages, based on evidence, need to be designed and disseminated to those women at highest risk.

Role of the media and industries in public education campaigns

The role of the media is of particular importance in correcting misinformation, which eventually circulates on the Internet such as the current anti-globalisation agenda, the

widespread distrust of 'big pharma' and, in many countries, concerns about vaccination and in particular fears of 'vaccine overload'.

The media is able to cover HPV related news, such as the introduction of new vaccination strategies or scientific developments, and personal stories about cervical cancer survivors. It has an additional role in questioning government about HPV vaccination policies. But the media should not be seen as a primary means of education. Scientists and professionals need to improve their interactions with the media and to the wider public providing easily understood "sound bites", and being available and passionate about the science. Problems arise when information gets out too late, not when information is provided up front.

Recent press articles spread the word that "new vaccines require virginity test", or "Our girls aren't guinea pigs" illustrating that the public needs clear and correct communication, to stress how ubiquitous HPV infections are, to dispel the view that only the promiscuous are likely to be infected. It must be clear that screening for cervical cancer remains a life-saving intervention for women whether vaccinated or not.

Industry, as the largest generator of data on products and their health outcomes, has a key role to play in providing information. Representatives of industry active in the area of cervical cancer, mentioned in a round table discussion that information about products is first provided to regulatory agencies, then to the scientific community through presentations in conferences and peer reviewed publications, and third, to health care professionals and the public through promotional activities, including marketing. Industry's reputation strongly depends on the safety and effectiveness of the products, and therefore, providing clear and complete information to regulatory bodies is a duty, and most post-marketing surveillance studies are done in collaboration with partners of governmental or non-governmental agencies to ensure neutrality of reported outcomes.

In this context, the European Federation of Pharmaceutical Industries and Associations (EFPIA) has issued the code of practice on relationships between the pharmaceutical industry and patient associations. This code builds upon the following principles that EFPIA, together with pan-European patient organizations, last updated in September 2006:

1. The independence of patient organizations, in terms of their political judgement, policies and activities, shall be assured.
2. All partnerships between patient organizations and the pharmaceutical industry shall be based on mutual respect, with the views and decisions of each partner having equal value.
3. The pharmaceutical industry shall not request, nor shall patient organizations undertake, the promotion of a particular prescription-only medicine.
4. The objectives and scope of any partnership shall be transparent. Financial and non-financial support provided by the pharmaceutical industry shall always be clearly acknowledged.

5. The pharmaceutical industry welcomes broad funding of patient organizations from multiple sources.

It was concluded that the media, industry and advocacy groups are essential players in a global effort to end cervical cancer.

Conclusions

Inspiring examples were presented and discussed throughout the conference. Four areas for communicating to the public and thereby improving health outcomes were identified by the participants. First, communicate about the diseases and its causes. Second, take a holistic approach, and communicate about primary and secondary prevention strategies. Third, target specific populations and communicate in a culturally appropriate and sensitive manner. Fourth, communication tools and messages need to be evaluated and monitored for both vaccination and screening.

However, it is apparent that the greatest expenditure for communicating about HPV diseases and prevention are implemented in countries that do not have the highest burden of disease. Stakeholders, players, constituencies, and scientists need to make sure that proper and equitable actions are taken, devising messages that will be made available to women who bear the greatest risk for HPV-related cancers. A network, forged at this First Patient Education Conference, should be built that will ensure that messages reach appropriate populations and cancer prevention programs become operational in places where prevention is most needed.

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Sonia Pagliusi^a

Herschel Lawson^b

Albert Singer^c

Joseph Monsonogo^{a,*}

^a *Departamento de Inmunización, Vacunas y Biología,,
Organización Mundial de la Salud, Ginebra, Switzerland*

^b *Center for Diseases Control, Atlanta, USA*

^c *Whittington Hospital, London, UK*

* Corresponding author at: EUROGIN, 174 rue de
Courcelles, 75017 Paris. Tel. +33 144400120.
E-mail address: jm@eurogin.com (J. Monsonogo)