

Italian women and HPV prevention. Knowledge, fears, uncertainty on Human Papillomavirus and the relative vaccination: dual research approach

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ABSTRACT

BACKGROUND: The main purpose of this study was to identify and describe knowledge, beliefs and attitudes towards Human Papillomavirus (HPV) infection and HPV vaccination among Italian women aged between 18 and 55.

METHODS: 6 Focus groups, in each of which 8 women took part, held in 6 different locations and a survey on a representative sample of 3 500 Italian women aged between 18 and 55, with oversizing for three regions (Lombardy, Latium, Sicily). The survey was conducted by telephone using the CATI (Computer Assisted Telephone Interview) technique, in September 2011, adopting a structured questionnaire. Data were codified and statistical analysis was computed using SPSS software.

RESULTS: Italian women have only a partial, even superficial, knowledge of pathologies associated with HPV, and also their information on the purpose of prevention activity, in which they choose to participate, is more generic than one might expect. The weakness of the information framework is partly due to the fact that the main source of information is the mass media, mainly the press and television, and to a lesser extent the Internet, and that information is random and fragmented.

Information about HPV and the possibility of vaccination often overlap, and it is the specific occasion of contact with the ASL (local health authority) vaccine services, providing information to youngsters that are the target of the free campaign, that is central in gaining access to information about the virus and vaccination, especially for the mothers of adolescent daughters. The vaccine campaign not only plays a key role in providing information about HPV and about the vaccination, but also ends up by influencing the notions and beliefs that Italian women hold about this vaccination.

CONCLUSIONS: Only a small portion of the female population, directly involved in the free vaccination scheme for adolescents, has actually been given information, often partial, on this subject. A crucial issue for future health promotion campaign in this sector is information, since women exposed to the highest level of qualified and targeted information, mothers of vaccinated girls, believe that the information available is generally inadequate.

Key words: Health information, Sexual behavior, HPV prevention, Free vaccine campaign

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INTRODUCTION

The research into information acquired by Italian women regarding Human Papillomavirus (HPV) and HPV vaccination, conducted by Censis

in 2011 (1), sought to obtain a clearer picture of the knowledge, views and attitudes of Italian women on the question of preventing cervical cancer and related lesions (2), with special reference to information on and propensity to make use of the HPV vaccine. Firstly, Italian women's

approach to preventing (3) cervical cancer, and more generally disorders of the reproductive system, was analysed, also looking at attitudes to vaccinations in general as a prevention strategy, in order to ascertain whether and to what extent these aspects might have a bearing on the level of knowledge about HPV and about the awareness of and attitudes to HPV vaccinations. The analysis of these aspects, which formed the basis of the study, centred not only on the Italian 18-55 year female population but also on more specific targets (mothers of adolescent girls (4), young women potentially eligible for facilitated access to the vaccination via social pricing, adult women) to examine the possible impact of public sector policies to combat HPV infection (1) on possible differences regarding access to information on the virus and relative vaccination (5).

METHODS

The research included a preliminary qualitative study (6) designed to analyse not only knowledge and attitudes but also fears and resistance to HPV and the relative vaccination by means of 6 Focus groups (7), in each of which 8 women took part, selected for their personal details and cultural traits and direct experience of the HPV vaccine.

Focus group meetings, held from 4 to 10 March 2011 in 6 different locations, lasted a little less than 3 hours. They were designed bearing in mind two basic modes of contact (actual or potential) with the vaccine, in the form of direct contact with the vaccination (youngster/young women target) and responsibility for the vaccination of daughters (and possibly sons, mother/adult women target) (Table 1).

TABLE 1

MACRO-REGIONAL AND DEMOGRAPHIC DATA DISTRIBUTION OF FOCUS GROUPS		
	Youngster/ Young women target	Mother/ adult women target
Northern Italy	18/26 in Milan	36/55 in Verona
Central Italy	27/35 in Latina	36/55 in Rome (100% not vaccinated)
Southern Italy	18/26 in Catania	36/55 in Naples

Focus group results formed the basis for the quantitative analysis (8), the second step of the study, a survey on a representative sample of 3 500 Italian women aged between 18 and 55, with oversizing for three regions (Lombardy, Latium, Sicily).

The error margin for all 3 500 valid interviews conducted, at a significance level of 95%, was +/- 1.7%.

This survey was conducted by telephone using the CATI (Computer Assisted Telephone Interview) technique, in September 2011, adopting a structured questionnaire prepared by the Censis research group based on the findings of the qualitative study.

Data were codified and statistical analysis was computed using SPSS software. Descriptive statistics were produced for all variables. Cross tabulation compares the main socio-demographic variables.

RESULTS

Knowledge of HPV: women informed, but with many doubts

Focus groups showed up basic points regarding the perception of HPV, which were then confirmed by the results of the survey.

The first impression is that women are generally aware of what HPV is, as confirmed by some spontaneous replies emerging in the groups, but when the level of knowledge was gauged there emerged a good deal of uncertainty and inaccuracies.

Recurring elements of knowledge are:

- sexually transmitted disease (but with the overriding idea of complete unprotected sex);
- cervical cancer, as an effect of HPV, while there is a more doubtful association with cancerous forms in other zones; there is an even more marginal association with genital warts and lesions that may lead to tumours (a possibility partly known only by the more informed young women in the 18/26 age group);
- women as victims of the virus, as a consequence of the pathology associated with HPV (cervical cancer), and of the free vaccination scheme for 11-year-old girls, while young males tend to be considered as "healthy carriers" (one or two young women know they can have minor pathologies such as genital warts, but they are very much in the minor-

ity). There is however no knowledge of the remoter possibilities that the virus might cause forms of tumours in men too. Women with lower educational levels do not associate males with HPV.

Notions on the virus (damage, means of transmission, prevention strategies, etc.), are thus only partially known and correctly established, and in a confused and fragmented manner, possibly with related fears. HPV is perceived as being underhand, treacherous, asymptomatic, and can be latent and fail to manifest. It is unclear whether it is always dangerous or dangerous only if it manifests, and above all how the danger presents itself. This uncertainty has an indirect bearing on the perception of the usefulness of the vaccine.

Survey data also demonstrate that Italian women have only a partial, even superficial knowledge of pathologies associated with human Papillomavirus. Although 80% of interviewees said they knew what HPV was, and the majority of them were aware of its essential traits and the more serious consequences of the infection (94.2% of respondents saying they knew what HPV was also knew that the virus in question was responsible for a number of tumours, especially cervical cancer, 82.7% knew that it can cause a number of pathologies of the genital apparatus, both benign and malignant, but that it often remains com-

pletely asymptomatic). But less than half of the women associated HPV with genital warts, and almost 70% believed that the virus affected only women.

This is partly related to the uncertainty found regarding transmission mechanisms, in relation to which the idea that the virus is spread through complete sexual intercourse is predominant (67.5%), and accordingly that the use of condoms serves as adequate protection (51.9%), while less than 20% of respondents knew that it is not possible to fully eradicate the risk of contagion when one is sexually active (Table 2).

The dissemination of correct information on HPV during focus group meetings (through reading of concept material describing HPV) was a chance for participants to gain an understanding of the dangerousness of the virus, and led to two types of macro-reactions, partly resulting in increased alarm and anxiety:

- on the one hand, an increased need for further information (“how can one protect oneself, what treatment is there?”)
- on the other, following an increased need for protection, there is an increased desire – both emotional and rational – for the vaccine, indeed doubts emerged about ongoing vaccine initiatives, deemed to be inexplicably inadequate in relation to the seriousness of the problem (“why do they vaccinate only twelve year olds? Why only girls?”).

TABLE 2

TABLE 2 – MEANS OF TRANSMISSION OF HPV, BY GEOGRAPHIC AREA (%)

	North West	North East	Centre	South and Islands	Total
Through complete sexual intercourse	69.0	70.0	64.4	66.9	67.5
Through other sexual relations (petting, contact with genital mucosa)	37.8	39.3	26.2	41.7	37.0
Through use of public toilet facilities (lavatory, shower, sauna, etc.)	9.8	11.6	10.7	12.0	11.1
Through the use of or contact with contaminated objects (towels)	8.5	10.7	10.9	9.4	9.7
Through blood transfusions, or sharing syringes	4.1	4.2	4.1	7.4	5.3
Through close contact with an infected person (handshake, kiss, sneeze, etc.)	4.2	2.9	7.3	2.8	4.1
Other	2.6	1.3	3.7	1.4	2.2
Don't know	12.5	15.5	12.8	13.0	13.3

The total does not amount to 100 as more than one response was possible

Source: Censis 2011 survey

Default prevention

The concern about inaccurate information is a recurring element of women's approach to the more general question of prevention, as the sample survey showed.

Even though the majority of women have regular access to gynaecological examinations (66.5% of Italian women say they have a gynaecological exam at least once a year) and to Pap smears (54.2%), information on the purpose of prevention activity, in which they choose to participate, is more generic than one might expect.

Less than one woman in three knows precisely the purpose of the examination, i.e. to quickly diagnose and screen for the presence of cervical cancer, even though a little less than 60% believe the Pap smear to have the generic function of preventing tumours of the reproductive apparatus. Thus it is true that there is a good level of awareness in relation to the fundamental importance of early diagnosis, even though information is non-specific, but one or two differences emerge, in terms of both knowledge and attitudes, in different areas of the country, with southern Italy being the area where information and awareness of prevention appears to be least widespread, especially among women with lower educational levels (9).

The dualism of information about HPV and the vaccine: from generic (media) to specific (ASL vaccine service)

Uncertainty as to the specific purpose of preventive behaviour in relation to levels of knowledge about HPV and relative vaccination is partly due to the fact that the main source of information mentioned during focus group meetings and indicated at length in the survey is the mass media (10): mainly the press and television (11), and to a lesser extent the Internet.

The question of HPV vaccines too is placed in a generally and confused fragmented information framework, on the subject of which focus group participants voiced doubts and uncertainties.

This question 'raised argument' in group settings, with puzzlement and doubt prevailing even among those who have been vaccinated or have vaccinated their daughters.

It emerged on this crucial aspect that:

- there is a widespread lack of information about the vaccine, related to the lack of certain, objective news, that can help to guide women. The information obtained from the mass media is random and fragmented, while official information sources are basically the school (for the target of free vaccination at

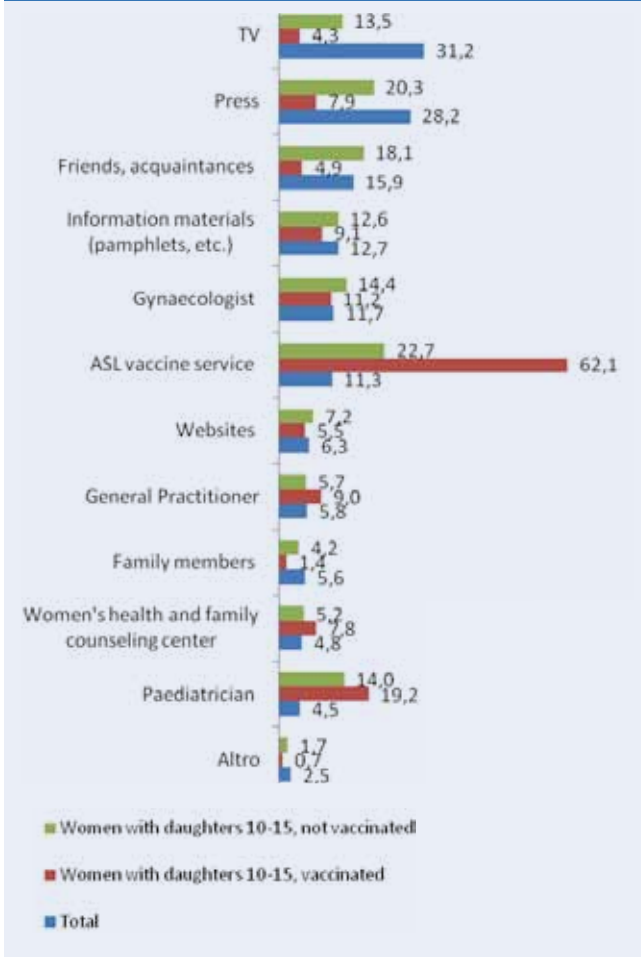
the age of eleven), and the vaccine service that sends out direct calls for cohorts interested in the free vaccination campaign. The role of information provider played by physicians (gynaecologist/paediatrician/general practitioner) appears to be reduced, although, when contacted in the event of doubts or following access to information from other sources, their views can become decisive (12);

- the vaccine has brought attention to the HPV virus, so prevention has in a way brought forward the time of awareness of the "danger to be prevented". This produces a logical and psychological short circuit, which partially hampers the path towards the vaccine, in particular in relation to other compulsory and optional vaccines;
- those excluded from the free vaccination scheme do not receive controlled, uniform information on the vaccine, and this has two consequences. Either one knows little about the matter (e.g. 27/35 year olds from Latina), or "one loses oneself" in muddled, unclear information such as that obtained via the Internet.

The weakness of the information framework is confirmed by survey findings: the main sources of information, with regard to both HPV and the vaccination, are the press and television, basically at the same level, cited by 30-35% of interviewees, who have been exposed to such information on a generally occasional basis. The information provided by healthcare professionals has also played a marginal role, although the role of the gynaecologist has been greater. Nevertheless, for mothers who have had their daughters vaccinated, the role of ASL (local health authority) vaccine services has been important, and in a little less than half the cases these services have been the main source of information about HPV at the time of direct calls, proposing the vaccination for their daughters, and in 62.1% of cases the source of information regarding the vaccination, which does not however provide complete information on pathologies and on the benefits of the vaccination, but focuses on free vaccination schemes (Figure 1).

Information about HPV and the possibility of vaccination often overlaps (3 out of 4 women know that a vaccine is available), and it is the specific occasion of contact with the service providing information to youngsters that are the target of the free campaign that is central in gaining access

FIG. 1

MAIN SOURCES OF INFORMATION ABOUT THE HPV VACCINATION, WITH PRESENCE OF DAUGHTERS AGED 10-15 VACCINATED OR NOT VACCINATED (%)


Source: Censis survey 2011

to information about the virus, especially for the mothers of adolescent daughters.

Both the qualitative analysis and the sample survey cleared showed that the vaccine campaign not only plays a key role in providing information about HPV and about the vaccination, but also ends up by influencing the notions and beliefs that Italian women hold about this vaccination.

Attitude to HPV vaccine

The Focus groups made it possible to examine ideas about the vaccination in greater depth, with an analysis of the views and attitudes of participants, based on some strategic themes (Figure 2).

Age is the first problem, with the prevalent belief being that the vaccine “must be given in the age of puberty”, and there is some confusion

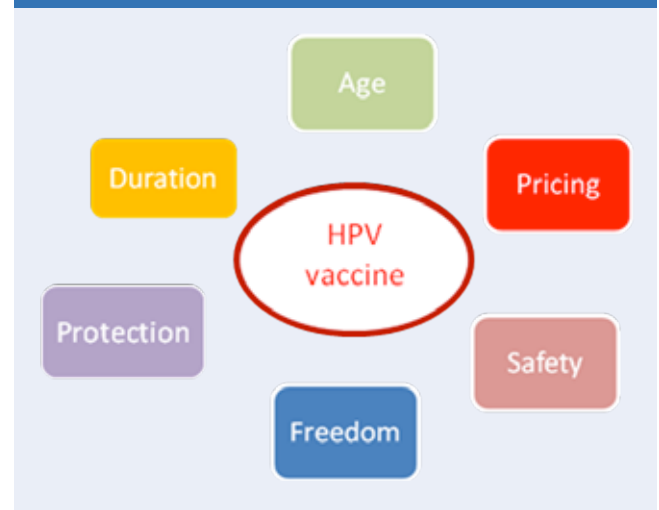
about the current healthcare programme and clinical recommendations for the vaccine.

There is a good deal of uncertainty about the possibility of adult women being vaccinated, and there is little information about programmes for gaining access to the vaccination as part of a social pricing scheme in place in some regions for women up to the age of 26.

With regard to the duration of the vaccine the information is available, often only vaguely, for targets “in the age” of the free vaccination scheme, and these are the best informed group. A critical and relevant point is the fact that the vaccine, having only been recently introduced, offers no guarantees that it will last a lifetime or a long period of time (women generally believe it will last for about 5/7 years). This is an element which, in the view of those questioned, might lessen the strength of the motives behind the vaccination and of resulting psychological protection, in part because this does not conform to the established habits with vaccines (or with the perception, which is not always correct, that the vaccine protects “for life” or that a booster dose should be given within a set time frame). This creates the danger that the HPV vaccine is still in an “experimental” phase, and so is of limited effectiveness, in this case in terms of duration.

The related question of safety is however much less present, and partly appears to be related to the presence of the public free vaccination campaign, which is deemed to be an element that provides a guarantee of reliability. There is some uncertainty about this aspect in the opinions of

FIG. 2

VIEWS AND ATTITUDES OF PARTICIPANTS, BASED ON SOME STRATEGIC THEMES


physicians, gynaecologists and family paediatricians, with the more general impression that the views of different healthcare professionals do not always concur.

Not everybody is aware of the question of pricing (outside the free vaccination programme), but there is a generally widely held belief that the cost of the vaccine is very high, and the estimate given by interviewees was quite uniform (500-600 Euro). Little or nothing is known about opportunities relating to social pricing, and in discussions the price is cited as a deterrent, becoming a sort of "mental alibi", apparently rational in nature, so as to avoid the vaccination, or is brought up as an element of social injustice, especially when considering the awareness of the potential seriousness of HPV (in particular in the Centre and South of the country; among youngsters aged 18/26 that are not economically independent and among mothers having more than one daughter).

Freedom is another element to be considered, and is a value that is perceived differently by target groups (especially by the more extreme groups):

- more conservative mothers may perceive the vaccine as a dangerous 'allowance', consenting to a sexually disorderly and amoral life for their daughters, especially if given at a very early age, and indeed this has served as a deterrent to vaccination;
- youngsters with higher educational levels believe the vaccine offers the possibility of a more tranquil and relaxed sexual life, and at least in theory this is a factor that works in favour of the vaccination.

Finally, the value of protection emerged during the course of the focus group meetings, taking on two rather contrasting yet basically positive meanings. The real possibility of protecting oneself against feared forms of tumours represents a hope for the future, and is an aspect that particularly affects mothers.

There are however elements of slight doubt as to the effectiveness of the vaccine, bearing in mind the many strains of the virus, especially for those that have superficial information about the fact that the vaccine covers only the main strains, which are however the cause of about 70% of the cases of cervical cancer, and about the need to take in any case the Pap Smear, since in a garbled way, and for someone that is aware of the question, it may appear to be a sign that the vaccine may not be totally effective.

Finally, the possibility of extending the vac-

ination programme to males was viewed positively, especially by the mothers of adolescent sons, and was indicated as being key to the effective curbing of the spread of the virus.

Focus group meetings did however refer to possible difficulties: it was mentioned that males did not have the habit of "intervening" on their body by way of health prevention, and it was suggested that free vaccinations should be facilitated in the age of puberty, just as for young girls, adopting "automatic" mechanisms rather than relying on conviction. There was also a quite widely held belief that the time is not yet ripe for a real awareness of the damage that HPV can cause to men, and consequently protection through vaccination is basically experienced as a question of protecting women.

The prevailing attitude to the HPV vaccination is in any case positive, and again this aspect is borne out in the survey: only about 30% of interviewees were not interested in the vaccination, for themselves or their daughters. Reasons given for interest in the vaccine that were most cited were the trust in medical and scientific progress and the possibility of combating a very dangerous disease.

Furthermore, interest in the HPV vaccination, and in relative choices to be made, primarily for their daughters but also for themselves, is also influenced by cultural attitudes to vaccinations in general, which are largely favourable (only 4.6% of interviewees said they were against vaccinations because they felt them to be dangerous). The most common stance (44.1%) is that of a prudent outlook, disregarding ideological views in favour of or against the vaccination as a matter of principle, but assessing single situations and being guided on a case by case basis by the expert advice of physicians. A little less than 30% of interviewees said they were in favour of only compulsory vaccinations which, having been recommended by the Italian NHS (National Health Service), are deemed to be reliable almost by definition.

Nevertheless, the percentage of Italian young girls, adolescent girls and women up to the age of 55 who have had the vaccine is 7.2%. This figure naturally varies by age class, and mirrors the history of national and regional choices made on the subject of free vaccinations for 11-12 year old cohorts, and more generally that of market penetration methods.

It thus appears that 62.2% of 14-year-old girls have been vaccinated, namely those girls who in 2008, the year vaccination campaigns began, were 11 years old.

The percentage falls slightly for current 13 year olds (59.9%) and 12 year olds (54.3%), showing up a trend that is probably related to a drop in participation in free vaccination campaigns.

The data clearly show the lack of penetration of the vaccination among adult women, and more generally its limited diffusion outside the free vaccination scheme. The use of economic incentives offered by Regions for the vaccination of young women may also be deemed to be extremely low, in view of the low percentage of women aged 18 and above that have been vaccinated (2.9%). In over 70% of cases indeed the vaccination was part of the free campaign for given cohorts, while 4% of the sample of vaccinated women had free vaccinations as part of an experimental project, and 16.1% of the sample paid in full for the vaccination. Only 10.2% made use of the price subsidy initiative.

The evaluation of free vaccination campaigns yielded generally positive opinions, with the large majority of respondents (80.6%) in agreement that the free scheme should be extended to older girls, providing they have still not engaged in sexual intercourse. Widespread agreement (78%) was also obtained about the possibility of extending the free vaccine campaign to males of the same age.

The crucial issue is again that of information: 4 in 5 women argue that available information on HPV and the relative vaccination is unclear, and 60% of mothers of vaccinated girls, i.e. women exposed to the highest level of qualified and targeted information, believe that the information available is generally inadequate (Figure 3).

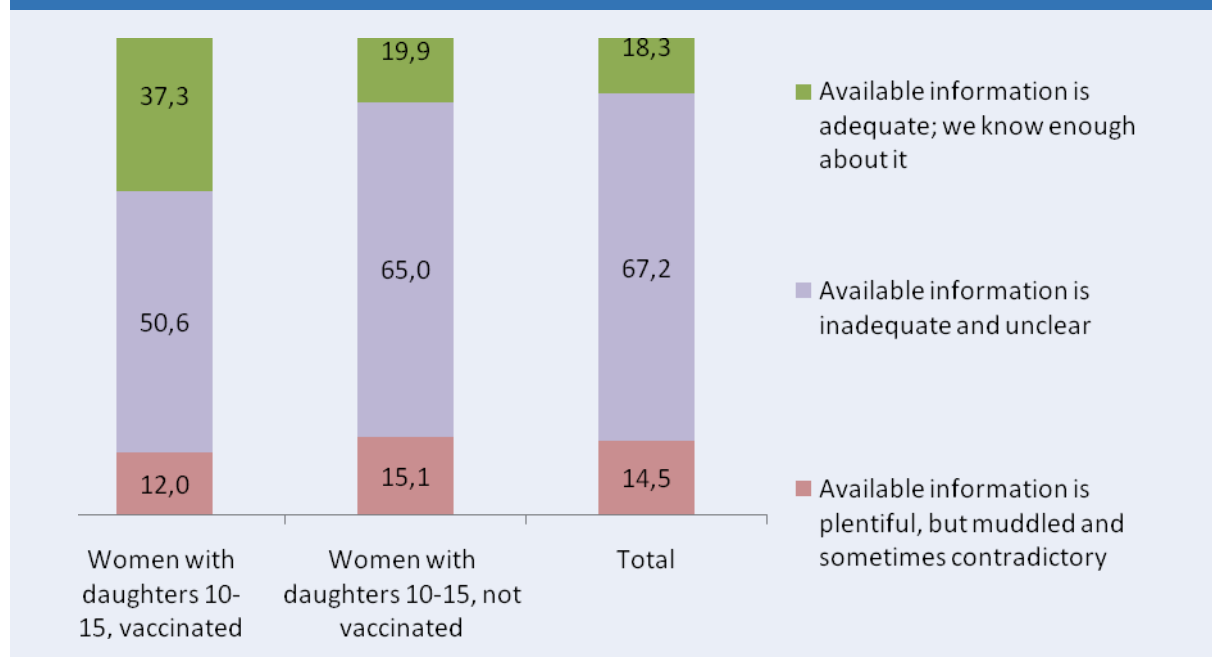
CONCLUSIONS

The study demonstrates that Italian women have only a partial, even superficial knowledge of pathologies associated with HPV. Although the majority said they knew what HPV was, and were aware of its essential traits and the more serious consequences of the infection, less than half of the women associated HPV with genital warts, almost 70% believed that the virus affected only women, and regarding transmission mechanisms, the idea that the virus is spread through complete sexual intercourse is predominant, and accordingly that the use of condoms serves as adequate protection

The concern about inaccurate information is a recurring element of women's approach to the more general question of prevention: even though the majority of women have regular access to gynaecological examinations and to Pap smears, infor-

FIG. 3

EVALUATION OF WOMEN ON AVAILABLE INFORMATION REGARDING HPV AND VACCINATION, HAVING DAUGHTERS AGED 10-15 VACCINATED OR NOT VACCINATED (%)



Source: Censis survey 2011

mation on the purpose of prevention activity, in which they choose to participate, is quite generic.

The weakness of the information framework is partly due to the fact that the main source of information is the mass media (13), mainly the press and television, and to a lesser extent the Internet, and this information is random and fragmented (14).

The role of information provider played by physicians (gynaecologist/paediatrician/general practitioner) appears to be reduced, although, when contacted in the event of doubts or following access to information from other sources, their views can become decisive.

Information about HPV and the possibility of vaccination often overlaps, and it is the specific occasion of contact with the service providing information to youngsters that are the target of the free campaign that is central in gaining access to information about the virus, especially for the mothers of adolescent daughters. The role of ASL (local health authority) vaccine services has been important but often vaccine services do not provide complete information on pathologies and on the benefits of the vaccination, but focus on free vaccination schemes.

The vaccine campaign not only plays a key role in providing information about HPV and about the vaccination, but also ends up by influencing the notions and beliefs that Italian women hold about this vaccination. Interviewed women tend to blur public healthcare choices with vaccine recommendations, for which reason they believe they are effective only for eleven-year-old girls, as that is the target of the free vaccination campaign. This is also why they are led to believe that the problem has nothing to do with men.

The possibility of extending the vaccination programme to males was viewed positively, especially by the mothers of adolescent sons, and was indicated as being key to the effective curbing of the spread of the virus.

The crucial issue is information, since the mothers of vaccinated girls, i.e. women

exposed to the highest level of qualified and targeted information, are also not duly informed and believe that the information available is generally inadequate.

In practice, only a portion of the female population, that directly involved in the free vaccination scheme for adolescents, has actually been given information on this subject, but the gradual decline over the past couple of years in the number of vaccinated girls in the age range eligible for free vaccinations shows that there has been a drop in interest in the question.

In order to achieve the strategic goal of HPV prevention pursued by the Italian NHS, in part through free vaccination campaigns and access through price subsidies, it is evidently necessary to step up efforts centring on the question of HPV vaccination.

The first step is to rely on the influential position that Italian women attribute to the NHS in order to improve the level of information on the virus and the relative vaccination, overcoming the uncertainty and superficiality characterising the current awareness of interviewed women.

It is also necessary to strengthen the role of information providers and guides of two essential actors of the system: on the one hand, ASL vaccine services, which have thus far been the only true effective information outlet on this subject, but often limited to the free vaccine campaign, without this necessarily entailing the supply of complete information on the virus, pathologies and the vaccination, on the other, attending practitioners, from gynaecologists to paediatricians, who are called upon to work more intensely as expert guides, and who can be a strategic and close source of information for a prevention choice which, in order to be really effective, needs to be made known to a wider audience.

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