

Brief Research Report: Uncertainty-Inducing and Reassuring Facts About HPV: A Descriptive Study of French Canadian Women

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We sought to describe information that makes women feel (1) uncertain and (2) reassured about their human papillomavirus (HPV) status and the potential health implications of an HPV DNA test result and (3) to examine information seeking after receiving their result. Thirty women (previously tested HPV negative) read

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factual information on HPV and cervical cancer and were asked which facts were uncertainty inducing and which were reassuring. Twenty-four facts reassured women of their HPV negative status, 11 facts made women feel uncertain, and 10 facts made them feel both. The most common reason for seeking information in the future was receiving a positive test result. The authors outline what specific facts about HPV health providers can emphasize to alleviate anxiety and encourage women to feel reassured of their low cancer risk following a negative test result.

Some types of the human papillomavirus (HPV) can lead to genital warts or cause no clinically evident lesions, whereas others cause cervical cancer (Trottier & Franco, 2006). HPV testing is a more sensitive screening test to detect cervical precancerous lesions compared with Pap cytology, which is less sensitive (i.e., high rates of false negatives; Mayrand et al., 2007). The greater sensitivity of HPV testing may allow for longer intervals between screening, and it may be more cost effective by reducing the number of referrals to colposcopy compared with Pap testing (Mayrand et al., 2007). In this study we are the first to investigate whether or not providing women with information about HPV and HPV testing reassures or creates uncertainty in women. We provided women with factual information about HPV and sought to describe what makes them feel (1) uncertain and (2) reassured about their HPV status and the potential health implications of their result. Another objective was to examine information-seeking behavior after receiving results and the reasons for such behavior.

The rapidly evolving field of HPV research has led to numerous attempts at developing clear and satisfying information about HPV (e.g., Gilbert, Alexander, Grosshans, & Jolley, 2003). Women who previously have tested HPV positive have greater HPV knowledge (Tiro, Meissner, Kobrin, & Chollette, 2007) and are more likely to seek information compared with women receiving negative test results, who represent the majority of women (McCaffery & Irwig, 2005). Women who receive HPV negative results may thus receive or seek less HPV-related information, rendering them less aware of the possibility of future infection when their risk profile changes (e.g., new sexual partner) and placing them at greater risk for lower adherence to screening recommendations. Moreover, receiving clear and accurate information *prior* to receiving a positive test result may help alleviate anxieties, enabling the person to ask relevant questions at the time of diagnosis, thus obviating the need to seek information from other, potentially confusing sources (e.g., the Internet) in the future (McCaffery & Irwig, 2005). In sum, educational messages aimed at HPV negative women are essential in order to prevent misinformation, minimize confusion, and equip them for making decisions about screening and for interpreting their test results (Tiro et al., 2007).

Several researchers have examined women's psychological responses to positive HPV DNA test results (e.g., Maissi et al., 2004) as well as women's informational needs (e.g., Anhang, Wright, Smock, & Goldie, 1999; Brown et al., 2007; Waller, McCaffery, Nazroo, & Wardle, 2005). The researchers found indirect evidence (i.e., they did not directly ask women) for information about HPV that induced uncertainty (Anhang et al., 1999) or was reassuring to women (Waller et al., 2005). They did not pinpoint the specific facts, however, that foster feelings of reassurance and uncertainty. We sought to identify specific information that health providers can use to help women to feel reassured of their low cancer risk following a negative test result.

Information seeking is one desirable behavioral outcome after receiving a negative test result (future screening being another) because information aids in making decisions about screening (e.g., through assessing one's risk), and it helps to equip women to deal with a positive result, if they ever get one (Hinds, Streater, & Mood, 1995). Rosen and Knäuper (2009) found that among untested women, uncertainty about one's HPV status led to more information seeking. The third objective is therefore to examine whether women who previously tested negative sought additional information and the reasons for their behavior.

METHOD

Participants

Thirty women were recruited in February–May 2006, as a subset of participants enrolled in the Canadian Cervical Cancer Screening Trial (CCCaST), a randomized controlled trial comparing the efficacy of Pap versus HPV tests in screening for cervical cancer (Mayrand et al., 2006). CCCaST participants were women aged 30–69 years, from Montreal and surrounding municipalities (province of Quebec) and from St. John's (Newfoundland). They were enrolled from 30 medical practices in 2002–2004, and each had two screening tests at recruitment: an HPV and a Pap test. Further details on the CCCaST methodology and participant information can be found in Mayrand and colleagues, 2006. Only women who had negative results on both screening tests were eligible for the present study called the Psychosocial Impact of Cervical Cancer Screening (PICCS). For logistic reasons we contacted only those participants living in the Montreal area. Participant and nonrespondent characteristics are reported in Table 1.

Procedure

Ethics approval was obtained from both the McGill University and the Jewish General Hospital review boards in Montreal, Quebec. A sample size of 30 was

TABLE 1 Demographic Characteristics of Participants and Nonresponders

Characteristic	Participant <i>N</i> (%)	Nonrespondent <i>N</i> (%)
Age (median, range)	50.5 (31–63)	43 (29–67)
Marital status		
Single	7 (23.3)	152 (38.5)
Married/living with a partner	13 (43.3)	175 (44.3)
Divorced/separated/widowed	10 (33.3)	68 (17.2)
Education		
Elementary school	1 (3.3)	14 (3.5)
Incomplete high school	1 (3.3)	37 (9.4)
Complete high school	5 (16.7)	97 (24.6)
College	6 (20.0)	93 (23.5)
University	17 (56.7)	154 (39.0)
Birth control method		
None	17 (56.7)	173 (43.8)
Condom	6 (20.0)	67 (17.0)
Hormonal	2 (6.7)	53 (13.4)
Surgical: vasectomy/tubal ligation	4 (13.3)	62 (15.7)
Other	—	40 (10.1)
Lifetime number of sexual partners (median, interquartile range)	5 (8)	4.5 (8)
Number of sexual partners in the year preceding recruitment in the CCCaST study (median, range)	1 (1–6)	1 (1–35)

chosen based on Morse's (2000) suggestion that 20–40 participants should be sought when exploring a new research area. A random sample of 130 out of 9,370 eligible participants was selected using a random number generator. They were sent a letter of invitation and called to schedule a 60-minute one-on-one interview. It was necessary to contact a second and third random sample of 130 women each (395 total) through the same procedure until a sample of 30 was reached. Written informed consent was obtained from all participants. The first author (N.R.) reviewed the responses by the first 25 and last five participants and found that no new ideas were raised in the last five interviews, indicating that information saturation had been achieved (Krueger & Casey, 2000).

Collaboration between the American Society for Colposcopy and Cervical Pathology (ASCCP), the American Cancer Society, and the National Cancer Institute resulted in a patient education pamphlet entitled, "What Women Should Know About HPV and Cervical Health" (ASCCP, 2003). We received written permission to model our information pamphlets on this information to ensure that it was up to date and valid. We included additional information in response to frequently asked questions about HPV as suggested by previous research (Gilbert et al., 2003). Three pamphlet versions were designed for the PICCS study, containing 40, 26, or 17 facts about HPV, in order to examine the psychosocial impact of providing varying amounts of information about HPV to women. The text of pamphlets can be found at <http://ego.psych>.

mcgill.ca/perpg/fac/knaeuper/supplementalmaterial.htm. The reading grade level of the pamphlets was assessed using the Flesch–Kincaid readability scale (grade-level range, 0 to 12), which has been demonstrated to be reliable and valid (Kincaid, Fishburne, Rogers, & Chissom, 1975). The reading grade level score for all three pamphlets was between grades 9 and 10.

These pamphlets were used in the current study in order to simultaneously pilot test the pamphlets for clarity purposes for the PICCS study. The 30 women were randomly assigned to read one of these three versions. Column 2 of Table 2 identifies the number of women who received a specific

TABLE 2 Information About HPV Highlighted as Uncertain vs. Reassuring

Information	<i>N</i>	<i>N</i> Uncertain	<i>N</i> Reassuring
Cervical cancer can be prevented	30	0	17
HPV prevalence is 75%	30	12	8
Cervical cancer is rare	30	2	11
Most infections cleared by immune system	30	0	9
Possibility of undetected “dormant” infections	30	7	2
Impossible to determine when and from whom HPV was transmitted	30	4	2
Details of Pap test procedure	30	0	4
HPV is sexually transmitted	30	3	2
Consequences of HPV can be treated	30	1	3
HPV test detects all types linked to cancer	30	0	2
Details of HPV test procedure	30	2	0
1,350 Canadians diagnosed with cervical cancer/year	30	0	1
HPV test can complement the Pap	20	0	4
Removal of abnormal cells is a simple outpatient procedure	20	0	4
Prevention by monogamy/abstinence	20	0	3
Attend follow-up appointments after abnormal results	20	0	3
Condoms do not reliably protect	20	0	2
More sexual partners increases risk	20	0	2
Over 100 HPV types	20	1	1
Smoking increases risk of cell abnormalities	20	0	1
Different HPV types have different consequences	10	3	1
Some HPVs cause genital warts (noncancerous)	10	2	1
If both tests normal, low risk of changes in next 3 years	10	0	2
Two abnormal HPV tests does not mean cancer; it does mean more evaluation	10	1	1
Total number of facts: 24	n/a	11	24

Notes. HPV = Human Papillomavirus. Three women highlighted the fact “the virus is so common that having only a single lifetime partner does not assure protection” as reassuring. The authors feel that it is likely that these women, in reading and processing a large amount of information, may have read this sentence as “DOES assure protection” and thus felt reassured.

HPV fact. After reading the pamphlet, women were asked questions about the clarity of the information they read (for the PICCS) and about HPV facts that induced uncertainty and reassurance and about information seeking (for the current research questions). We hypothesized uncertainty reduction and reassurance to be some, but not the only, reasons why HPV negative women seek information.

Measures

Questions about uncertainty-inducing and reassuring facts. We examined the highlighted information that women indicated following these instructions: "Please read the brochure and highlight (with a marker) and label (in the margin) any information that makes you feel (1) uncertain about whether or not you have HPV or (2) reassured about your HPV status or your chances of getting cervical cancer." Respondents were told verbally to highlight any information that made them feel uncertain about the potential health consequences (i.e., the meaning of a positive HPV test result). Respondents also were told verbally to highlight information that might make other women feel uncertain or reassured. Two coders (N.R. and G.P.) independently counted the highlighted information and came to the same result (i.e., achieved perfect inter-rater reliability) about the number of highlighted facts in each of the 30 participants. The results were calculated by counting the number of women who highlighted the HPV fact. We interpreted the results descriptively, with the number of women who received each specific HPV fact in mind, in order to identify specific facts that health providers can use in their conversations with HPV negative women.

Questions about information-seeking. Questions about information seeking included the following: "Did you seek more information about HPV after your first HPV test?" If yes, "Why did you seek more information?" If no, "Why did you not seek more information?" and "What could potentially make you seek more information in the future?" Responses were recorded verbatim by the interviewer. Two coders (N.R. and G.P.) independently reviewed the recorded responses to the questions. Like responses were counted and labeled according to their content. All participants were asked the same set of questions, and thus the results for this section were calculated in percentages.

RESULTS

Uncertainty-Inducing vs. Reassuring Facts About HPV

Overall, 24 facts about HPV reassured women of their HPV negative status, 11 facts made women feel uncertain about their own (or possibly other women's) HPV status or the potential health consequences of a positive

result, and 10 facts made them feel both reassured and uncertain. The facts are listed in Table 2.

Twenty women did not highlight any facts that made them (or would make other women) feel uncertain about their HPV status or the potential health implications of the result. Of the 10 women who did highlight information, five highlighted only one fact (HPV prevalence is 75%), whereas the remaining five women highlighted two or more. All of these women also highlighted facts that made them feel reassured. Twenty-four women highlighted at least one fact about HPV as reassuring in terms of their current negative HPV status and their future chances of getting cervical cancer.

Seeking Information About HPV

None of the women reported seeking more information after their first HPV test. The most common reason for *not* seeking information, given by over one-third of the women (11 women, 37%), was that they received a negative test result. Other reasons for not seeking information were that they relied on their health care provider for information (five women, 17%), they did not feel at risk (four women, 13%), they did not feel a need for more information (four women, 13%), and they did not know what HPV was (four women, 13%). Similarly, the most common reason for seeking information in the future was if they received a positive Pap or HPV test result or if someone close to them received a positive result (22 women, 73%). Women also felt motivated to seek information if they saw pamphlets or advertisements about HPV (four women, 13%) and if their doctor encouraged them to do so (three women, 10%).

DISCUSSION AND CONCLUSION

Discussion

We found that for HPV negative women, more than double the number of facts about HPV were perceived as reassuring compared with uncertainty inducing. The most commonly highlighted reassuring facts included that cervical cancer is preventable and rare, and that HPV infections are very prevalent and usually are cleared by the immune system.

Of the 11 facts that were perceived as uncertainty inducing, 10 also were highlighted by at least one woman as reassuring. The high (75%) lifetime prevalence of HPV frequently was highlighted as both uncertainty inducing (12 women) *and* reassuring (eight women). On the one hand, this fact may induce uncertainty about one's current or future HPV status given the high probability of infection at least once in a lifetime. On the other hand, women may feel reassured in knowing that they are not alone in contracting HPV. The fact that more women felt uncertain (rather than reassured)

about their HPV status due to this fact suggests it should be accompanied by additional reassuring information, as identified by the current research.

A fact about HPV that was, surprisingly, not highlighted as uncertainty inducing by any of the women was the fact that condoms do not reliably protect against HPV. Our result might reflect the fact that the majority (24 women, 80%) of the participants were older, had few partners, and did not report using condoms, therefore making the information on lack of protection personally irrelevant. This potential source of uncertainty could be explored further perhaps with younger women (<30 years) who are not in committed relationships and use condoms more regularly.

The majority of women in our study (20 women, 67%) did not highlight any facts as uncertainty inducing with respect to their own HPV status or the potential implications of a positive result nor did they think other women should feel uncertain if they tested negative. This finding is encouraging because some of the characteristics of HPV's natural history have the potential to make women feel uncertain about their HPV status despite a negative test result, and this uncertainty could lead to higher levels of worry or anxiety. Most information was perceived as reassuring, as indicated by the many facts that were highlighted as such. Feeling reassured is an appropriate response given that their last test result was negative and thus there is an extremely low possibility that they will be diagnosed with cervical cancer in the next 3 years (Smith, Cokkinides, & Eyre, 2006). It is possible that the type of information women find uncertainty inducing and reassuring may vary according to their personal risk profile (e.g., age, number of partners, etc.). Future research with diverse populations would elucidate potential moderators of the current results.

Women in our study did not seek any further information after their first test, purportedly because they felt they received all the information they needed about HPV. The most common reason for not seeking information was that they received a negative screening test. Similarly, the most common future motivator for seeking information would be receiving a positive test result or having someone close to them receive a positive result. Women also felt they would be motivated to seek information if they saw pamphlets or advertisements about HPV. Although the women in our sample did not seek further information, it is possible that they still would be interested should they be provided with information. Further, messages aimed at women who receive a negative test result are necessary because it helps them to take preventative measures and to be better able to understand and process the information they are given as they may be less distracted by anxiety over a positive result (Hinds et al., 1995).

The rapidly evolving field of HPV research sometimes makes it difficult to provide patients with clear and consistent information on HPV. Thus, cervical cancer program planners are fearful that women will not have the

information they need to feel reassured about their HPV status and their cervical cancer risk. We think, however, and the current results support, that this type of information will be readily available to women if HPV DNA testing were to become a standard practice for cervical cancer screening. And it seems that women who previously tested HPV negative mostly perceive this information as reassuring.

Although we found it very encouraging that most information about HPV was perceived as reassuring by most of the HPV negative women, women also should be counseled about the possibility of a changing risk profile. Indeed, if older women were to have an undetected (dormant) HPV infection or contract an infection in the future, then they would be in a higher risk group for cervical pathology. Women who receive an HPV positive test result may report more or different facts about HPV as uncertainty inducing or reassuring. Previous researchers have begun to identify what information may reassure (Waller et al., 2005) or induce uncertainty (Maissi et al., 2004) in women after undergoing HPV testing, and the current results add to this growing literature. It would be worthwhile to replicate the results with HPV positive women in order to specify comprehensively what facts about HPV may lead to different reactions depending on the HPV test result.

The small sample size, older age, and high educational status of our sample warrants caution in generalizing from the results. In addition, the method of selection may not have resulted in a random sample given the large refusal rate. We recognize the possibility of a participation bias based on the older age and high educational level of our sample. We assessed the reading grade level of our materials to be moderate (grades 9–10) and appropriate given the educational status of the sample, but the results might differ in a younger and less educated group of women. Researchers should replicate the results with a more heterogeneous sample. Previously, however, researchers, have shown that HPV knowledge, including confusion about HPV transmission and whether condoms or oral contraceptives protect against HPV infection, is poor, even among well educated samples (Waller et al. 2003). Indeed, although the women in our sample already had participated in CCCaST and thus had prior experience with HPV DNA testing, four women reported not having heard of HPV. Those women who had heard of HPV correctly answered only a little more than one-third of the questions on an HPV knowledge test correctly (the knowledge test was given for purposes related to the PICCS study). This level of knowledge is comparable with what usually is found in general population samples of women (Tiro et al., 2007; Waller et al., 2003).

Conclusion

We found that there are many facts about HPV that HPV negative women perceive to be reassuring in terms of their current negative status and future

risk of cervical cancer. Most women did not identify any facts that made them feel uncertain about their HPV status. Among those who did highlight uncertainty-inducing facts, all the women also highlighted facts that made them feel reassured. The high level of reassuring information may have counterbalanced the impact of the uncertainty-inducing information. Our results begin to inform health care providers and educators in delivering negative test results in a manner that accurately describes the characteristics of an HPV infection (potentially inducing uncertainty) while also emphasizing information that can reassure women of their low short term cancer risk. In the event that women continue to feel uncertain or anxious about their HPV status, we have described what specific facts about HPV may be perceived as reassuring. Health care providers and educators can emphasize these facts in order to alleviate anxiety and encourage women to feel reassured of their low cancer risk following a negative test result.

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