



## “I’m neither here, which would be bad, nor there, which would be good”: the information needs of HPV+ women. A qualitative study based on in-depth interviews and counselling sessions in Jujuy, Argentina

Lucila Szwarc, Victoria Sánchez Antelo, Melisa Paolino & Silvina Arrossi

To cite this article: Lucila Szwarc, Victoria Sánchez Antelo, Melisa Paolino & Silvina Arrossi (2021) “I’m neither here, which would be bad, nor there, which would be good”: the information needs of HPV+ women. A qualitative study based on in-depth interviews and counselling sessions in Jujuy, Argentina, *Sexual and Reproductive Health Matters*, 29:1, 453-463, DOI: [10.1080/26410397.2021.1991101](https://doi.org/10.1080/26410397.2021.1991101)

To link to this article: <https://doi.org/10.1080/26410397.2021.1991101>



© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 15 Nov 2021.



[Submit your article to this journal](#)



Article views: 728



[View related articles](#)



[View Crossmark data](#)



Citing articles: 1 [View citing articles](#)

# “I’m neither here, which would be bad, nor there, which would be good”: the information needs of HPV+ women. A qualitative study based on in-depth interviews and counselling sessions in Jujuy, Argentina

Lucila Szwarc <sup>a</sup>, Victoria Sánchez Antelo <sup>b</sup>, Melisa Paolino <sup>c</sup>, Silvina Arrossi <sup>d</sup>

a Research Fellow, Centro de Estudios de Estado y Sociedad/Consejo Nacional de Investigaciones Científicas y Técnicas, Buenos Aires, Argentina. *Correspondence:* lucilaszwarc@gmail.com

b Researcher, Centro de Estudios de Estado y Sociedad, Buenos Aires, Argentina

c Researcher, Centro de Estudios de Estado y Sociedad/Consejo Nacional de Investigaciones Científicas y Técnicas, Buenos Aires, Argentina

d Senior Researcher, Centro de Estudios de Estado y Sociedad/Consejo Nacional de Investigaciones Científicas y Técnicas, Buenos Aires, Argentina

**Abstract:** *The objective of this qualitative study was to explore the information needs of HPV+ women. We conducted 38 in-depth interviews with HPV+ women in the province of Jujuy, Argentina. The interviews included a counselling session to respond to women’s concerns and questions. Women perceived the information provided as good, despite having several doubts and misconceptions after receiving results of an HPV+ test. They expressed difficulties in formulating questions during the consultation due to shame, excess of information provided or lack of familiarity with technical language. They valued emotional support and being treated kindly by professionals. The perceived information needs that emerged as most important were: (1) the meaning of an HPV+ result and its relationship with cervical cancer evolution and severity; (2) continuity and timing of the care process; (3) information on the sexual transmission of the virus; (4) explanation of the presence or absence of symptoms. Women’s primary unperceived information needs were: (1) detailed information about colposcopy, biopsy and treatments and their effects (including fertility consequences); and (2) deconstructing the association of sexual transmission with infidelity. Sources of information included: (1) the health care system; (2) the internet; and (3) social encounters (close friends and relatives). It is crucial to strengthen the processes for delivering results, with more thorough information, improved emotional support and active listening focused on the patient, as well as to conceive new formats to provide information in stages and/or gradually, in order to facilitate women’s access to the health care system and the information they need. DOI: 10.1080/26410397.2021.1991101*

**Keywords:** HPV screening, cervical cancer screening, human papillomavirus, DNA testing, sexually transmitted diseases, information needs

## Introduction

The efficacy of the human papillomavirus (HPV) test as the primary cervical screening method has been widely proven.<sup>1–3</sup> HPV tests detect this asymptomatic, sexually transmitted virus which will regress on its own for most women.<sup>4</sup> However, the virus persists in a proportion of HPV positive (HPV+) women, who may develop pre-cancerous lesions in the cervix and, eventually, cancer.<sup>5</sup>

Thus, HPV positivity represents a relatively new diagnostic entity with ambiguous connotations; it indicates infection with an oncogenic virus, but infection does not necessarily mean cancer will follow. In a test-based HPV screening programme, triage tests are needed to identify which HPV+ women need further diagnosis and treatment procedures.<sup>6,7</sup> HPV+ women with normal triage are given the recommendation to

re-test in 18 months.<sup>4</sup> Evidence has shown that as a result of these characteristics of HPV testing, women might have difficulties in understanding HPV results. They often overestimate the severity of the result, fail to understand its ambiguity, express confusion about the sexual transmission of the virus, and confuse the HPV test with the Pap smear.<sup>8–12</sup> It has also been shown that an HPV+ diagnosis may carry a unique set of anxieties and stress for patients and their interpersonal relationships.<sup>13–16</sup> A study carried out in Argentina and Colombia (that used a scale specifically designed and validated to be used in screening contexts) showed that the highest psychosocial impact was measured in the *worries about cancer and treatment* domain, followed by the *sexuality* domain.<sup>17</sup>

Understanding of HPV results might be hindered by deficiencies in the patient-provider communication process. Indeed, several studies have found that, from the women's perspectives, health professionals very often do not provide sufficient or understandable information during results delivery.<sup>10,12</sup> A study carried out in Panama found that only half of the women reported discussing their health problems related to HPV infection with doctors and nurses.<sup>18</sup> In other countries, like Taiwan and the United States, women also reported having difficulties in conversations with their healthcare providers about HPV information.<sup>19,20</sup> These problems in communicating HPV results might increase women's lack of understanding regarding the screening process and the meaning of HPV positivity, which might result in higher psycho-social impact and reduced adherence to follow-up.<sup>11,12</sup> A study carried out in Argentina showed that women with abnormal tests who had the opportunity to discuss concerns about the following steps during the consultation had much higher adherence to follow-up than women who did not have that possibility (81% vs 19% respectively).<sup>21</sup>

"Information needs" have been conceptualised as a lack of understanding and knowledge regarding health issues, whether or not this lack is perceived.<sup>12,23</sup> In the context of HPV testing, "information needs" include doubts or confusions women express about the meaning of an HPV+ result and its implications.<sup>12,22,23</sup> Information needs will be highly dependent on information received during the medical consultation, but the consultation is not the only source of information available to women. It has been shown

that other main sources of information are the internet and close friends and relatives, especially when forms of communication with health providers about the screening process are not sufficient or adequate.<sup>22–24</sup> Understanding women's information needs and sources regarding HPV testing is thus essential in order to devise communication and counselling strategies aimed at reducing the psychosocial impact of HPV testing and increasing adherence to follow-up.

However, despite its importance, in Latin America little research about information needs during the HPV test-based screening diagnosis and treatment process has been carried out.<sup>10,17</sup> Research on women's information needs has mainly focused on HPV vaccination<sup>25,26</sup> or the follow-up and treatment process<sup>27</sup> in high-income countries.<sup>13,22,27</sup> No study from Latin America has qualitatively explored unperceived information needs regarding HPV and cervical cancer prevention, that is, issues about which women initially express having a good understanding, but which, when explored further, reveal significant misconceptions or gaps in the women's knowledge that they did not recognise. We are therefore reporting results from a study aimed at describing women's information needs, both perceived and unperceived, regarding HPV testing in Jujuy, Argentina, the first province to have introduced HPV testing in Argentina.<sup>28</sup>

### Materials and methods

This qualitative study was part of a larger investigation focused on women's perspectives regarding the process of delivering results and of adherence to follow-up in the cervical cancer prevention process. Qualitative design privileges an interpretative approach to social processes through a person's perspective, paying attention to the context where they emerge, and focusing on participants' experiences, as they were narrated.<sup>29</sup> This approach allows an understanding of the cultural and symbolic conception of health experiences and contributes to complementing the results of quantitative, clinical and epidemiological studies on cervical cancer prevention.

The fieldwork took place in June 2016 in the province of Jujuy, Argentina, where HPV tests have been available in the public health care system since 2012.<sup>28</sup> According to national screening guidelines,<sup>4</sup> HPV testing is indicated for all women aged 30 and over. Cytology is the triage test used

to identify HPV+ women who need immediate referral for colposcopy/biopsy. HPV testing and cytologies are taken at the same time, but cytologies are read only if HPV tests are positive.<sup>4</sup>

The province of Jujuy has an extensive development of health promotion activities. The primary health care system integrates approximately 700 paid full-time community health workers who twice yearly visit approximately 110,000 households for health prevention- and promotion-related tasks.<sup>28</sup>

### Participant selection

Eligible women were aged 30 and over, residing in the province of Jujuy, who had performed HPV testing during 2013 and had a positive result.

### Data collection

Community health workers contacted eligible women face-to-face at their homes and invited them to take part in the study. If they accepted, contact details were provided to a female interviewer with a social sciences and health counselling background, who visited women and carried out individual face-to-face in-depth interviews.

The interview consisted of two parts, both carried out during the same visit. In the first part, we used a semi-structured interview guide to collect data on women's perceptions of the delivery of HPV test results, the information provided by physicians, sources of information and information needs. In the second part of the interview, women were offered counselling aimed at answering their questions and discussing their feelings and concerns. Health counselling sessions are "[...] meeting points between the health care team and women so that women can get information and ask questions, expand their knowledge and express their fears."<sup>30</sup> One key aspect involves the listening skills of the counsellor, who provides information based on the knowledge, feelings, and experiences of each woman, without passing judgment. The counselling space that took place in the second part of the interview enabled a dialogue which started with careful listening to the women's experiences from the moment they were informed of HPV positivity. This allowed women greater reflection about their experiences in relation to the cervical cancer prevention process and the possibility to express doubts that had not emerged during the first part of the interview.

The interviews took place mostly in women's houses ( $n = 22/38$ ). However, some women preferred their workplaces (4), outdoor spaces like squares or benches (8), a coffee shop (1), or a consulting room in a health care facility (3). Although most of the interviews and counselling sessions were conducted in privacy, many women were looking after their children at the same time. On one occasion only, the husband of an interviewee was at home at the time of the interview, which caused the woman to interrupt her story twice, when he entered the room. In another situation, a woman who served in a family store agreed to participate if she could continue working, which caused interruptions during the interview. Interviews lasted on average 45 min.

All interviewed women gave their consent to the recording of the interview and to the use of the data obtained during the interview and counselling sessions. In order to ensure anonymity and confidentiality, pseudonyms were used to record and transcribe the interviews and counselling sessions. The study's protocol was approved by the Provincial Bioethics Committee of Jujuy in June 2012. Interviews were conducted in Spanish and analysis was done using the original Spanish text. The quotes used here were translated into English.

### Data analysis

The data were read and interpreted with the aim of identifying recurrent topics and patterns, following grounded theory research design. Rather than creating categories from a top-down approach, where the researcher imposes an analytical structure over the original participants' experience or meaning, grounded theory design follows a dialogical and emergent mode.<sup>31</sup>

Transcripts were analysed independently by two researchers later to compare, debate, and resolve the inconsistencies with the other members of the research team. Based on the women's interviews, we coded emergent categories as subthemes; "perception of the quality of information received," "information needs" (perceived and unperceived), and "information sources" were categorised as the main sub-aspects.

As a concept arising from the thematic analysis, we also distinguished between perceived information needs, related to the information needs which women perceive as such, and unperceived information needs, which refer to some aspects

that women consider that they understand, but about which they express significant confusion.

## Results

### Characteristics of the interviewed women

Table 1 shows the characteristics of the interviewed women ( $n = 38$ ). The majority (68%) resided in urban areas, 74% had achieved secondary education or less, and 71% had public health insurance. Of all the women, 71% had received their HPV results, whereas 29% had not picked up their results. 47% of all women had HPV+/normal Pap smear results, and 53% had HPV+/abnormal Pap smear.

### Perception regarding the information received upon the delivery of results

In general, while women considered that “the explanations they received were good” they also indicated that they were left with doubts, they did not understand the information, or that the explanations could have been clearer.

The perception of having received adequate explanations, but having unresolved questions, was related to their idea that they were responsible for understanding the information. The women also had the perception that they should have asked questions in a timelier manner.

*“The male physician gave me very clear explanations. Not the female physician, maybe because I didn’t ask, I didn’t know what it was.”* (Susana, 43 years old)

Some women expressed that “it could have been worse,” meaning that at least they were provided with some information.

*“Generally speaking, the care was good. At least they gave us some explanation.”* (María Alicia, 44)

Although one group of women had asked questions during the consultation, another group reported difficulties in asking, due to the shock produced by the result (associated with disease and death), due to shame or embarrassment in front of male professionals, or due to the difficulties regarding technical medical vocabulary.

*“There are things I didn’t ask that I remembered later. [...] The thing is at the moment I couldn’t – I got blocked. It must be fear. Then I remember.”* (Rosa, 49)

*“[...] I asked if I was ill, if it was contagious. [I was told] it was in the womb, to prevent cancer, or something like that. You people speak that*

**Table 1. Women’s characteristics**

|                            |   | <i>n</i> | %   |
|----------------------------|---|----------|-----|
| Total cases                | Women                                       | 38       | 100 |
| Age group (years)          | 30–39                                       | 17       | 45% |
|                            | 40–49                                       | 14       | 37% |
|                            | 50–70                                       | 7        | 18% |
|                            | <i>Mean: 49 years; range: 33–68 years</i>   |          |     |
| Educational level          | Primary complete/<br>secondary incomplete   | 22       | 58% |
|                            | Secondary complete                          | 6        | 16% |
|                            | Tertiary incomplete/<br>complete            | 10       | 26% |
| Economic activity status   | Economically inactive (out of labour force) | 14       | 37% |
|                            | Economically active (in labour force)       | 24       | 63% |
| Area                       | Urban                                       | 26       | 68% |
|                            | Rural                                       | 12       | 32% |
| Marital status             | Without a partner                           | 18       | 47% |
|                            | With a partner                              | 20       | 53% |
| Number of children         | 0   | 3        | 8%  |
|                            | 1–2   | 12       | 32% |
|                            | 3+  | 23       | 60% |
| Health insurance           | Public                                      | 27       | 71% |
|                            | Private/Social Security                     | 11       | 29% |
| Screening result           | HPV+/normal Pap smear                       | 18       | 47% |
|                            | HPV+/abnormal Pap smear                     | 20       | 53% |
| Picked up HPV test results | Yes   | 27       | 71% |
|                            | No  | 11       | 29% |



way. *I can barely understand anything.*" (Hilda, 39)

*"I didn't ask anything. Because I didn't dare, they were all male physicians."* (Mariana, 33)

Several women expressed that after the medical consultation they were left with unanswered questions that increased their fear of disease and death. In contrast, they expressed that the counselling space provided after the interview allowed them to understand the diagnosis and care they received, mitigating the emotional impact.

*"You don't know what a relief this is, because I deal with this every day. I wake up and it's the first thing I think about. Sometimes I go to bed crying for my children. [...] Now, I'm leaving relieved. Totally at peace. I'll sleep well. [...] It's nice to find a person [...] that can answer all my questions, because feeling like this is awful."* (Rosa, 49)

### Perceived information needs

The perceived information needs are the main topics women would have liked to ask about in the consultation and/or that they asked about during the counselling space of the interview. First of all, women would like to receive information about HPV infection: what it is and its severity, progression or persistence in their body, and its relationship with an abnormal Pap smear and cervical cancer.

*"I had the colposcopy done and I was told it was ok. I was explained [by the doctor] that there's a line there, and I'm here. I'm neither here, which would be bad, nor there, which would be good. I'm somewhere in the middle."*

*[What would you have liked to ask?]*

*"If it's possible to end up on the worst side. How long it could take or if it can disappear."* (Fernanda, 52)

*"What is it? Can you live your whole life with it [HPV]? Are white spots dangerous?"* (Rosa, 49)

Secondly, they would like to receive information about the way the virus is transmitted, either because it is unknown to them or because they have doubts about the effect on men or the possibility of transmission from men to other women.

*"I wanted to ask: What is the origin of the virus? Is it an infection? Is it something that comes with us or what?"* (Silvina, 41)

*"The first thing I asked him [the physician] was why. Why I got it. And I don't quite remember what he said to me. [...] but the first thing I asked him was about sexual relations."* (Susana, 43)

Thirdly, they would like to receive information to solve concerns about follow-up and treatments, and the steps and time lapses to follow in care.

*"I have a question about the treatment. If [the test] is positive, do they give me [vaginal] suppositories to treat it? And that's all the treatment is about?"* (Silvina, 41)

*"He told me that I had something like yeast. And I asked him if it was necessary to do it again. He told me 'If it doesn't go away, you'll have to.'"* (Mariana, 33)

Finally, they had doubts related to the lack of symptoms, or other gynaecological symptoms which they interpreted in association with the HPV result.

*"I said 'Doctor, but nothing hurts. I mop the floors, I do things. I lie on my stomach. Doctor,' I tell him, 'Nothing hurts. And I don't have any symptoms. How can that be?'"* (Elizabeth, 51)

*"Sometimes, I have a little [vaginal] discharge. And why is that? Is it related to HPV?"* (Mónica, 35)

### Unperceived information needs

Besides the perceived information needs, one unperceived information need was related to the moment and duration of the infection, incubation time and whether women should link infection to the sexual activity of their current partner. This is generally the result of women assuming infidelity once they learned about the sexual transmission of the virus.

*"And this caused an argument between us, because my children are his. And as a woman, my active sexual life, since I started until now, has been with him, not with other people."* (Silvina, 41)

A group of interviewed women reported that although they had understood the information about biopsies and treatments, after the intervention they discovered they had missed some important pieces of information referred to the procedure itself, what they were going to experience or/and what effects it would have on their bodies and health.

*“[When I got the result] I understood, but well I believed that, if my cervix was being removed, I couldn’t get pregnant again. This is exactly why I didn’t use contraceptives, I wasn’t using contraceptives and, I don’t know, for a long time I didn’t get pregnant. [...] And then I realized I was pregnant on the third month.”* (Marina, 38)

*“My mother said: ‘They take out your whole womb,’ and no, when I got there, no, it wasn’t like that, I got there and they only took out a small part of my womb, a sample and that’s it.”*

*[And you didn’t have time to ask the doctor what they were going to do to you?]*

*“No, no ... because ... it’s like that, fast, I mean, she got me my appointment, soon I had to go there. [Then] she only told me ‘I’m going to cut you, make a little cut.’ Nothing else. [...] It was an experience ... [that was] a bit traumatic.”* (Eva, 37)

As mentioned above, some women reported unplanned pregnancies that resulted from misinformation and lack of information regarding the effect of diagnostic/treatment procedures on fertility or the need to continue using contraception methods.

*“I didn’t quite understand what the doctor said [about the procedure] back then. That’s why I thought that I wasn’t going to get pregnant, because of the procedure. Then, when I got pregnant, I was afraid that something would happen to the baby.”* (Leonor, 36)

### Sources of information

Women reported consulting different sources to find out additional information about the screening process. Some women reported that they obtained additional information in unplanned encounters with community health workers or during consultations with clinical physicians or paediatricians they visited for other reasons, not within a consultation scheduled for this purpose.

*“I thought it was something serious. I felt paranoid and had a lot of doubts. And she [the community health worker I ran into on the street] calmed me down with her explanation.”* (Silvina, 41)

If these “opportunities” were not available, the sources of information were from outside the health system, especially close relatives (generally other women, such as mothers, daughters or friends) but also internet searches they or their relatives carried out.

*“My eldest daughter searched the internet and found out what it was. [...] She told me it was because of sexual intercourse, she explained something, but I told her not to worry.”* (Susana, 43)

Women reported that all through the screening/diagnosis/treatment process they consulted several sources, obtaining the information in pieces, as care was received. Women with similar diagnoses were an important source of information during this process.

*“I myself tried to research, to get more information about HPV. [...] I searched the internet ... [...]. I looked up HPV, then I found the causes, consequences, some symptoms [...]. Then I waited for some time, and later, again, I don’t know how I learned that it led to uterine cancer. [...] I went back because I had to have the test again, I saw the gynecologist again [...] besides, some friends had told me, they had been burned inside, or they said something like that, so I thought it wasn’t something serious ... such a serious disease.”* (Victoria, 43)

Women valued the source of information in relation to how it allowed them to cope with uncertainty and concern about the HPV results. Thus, the information received in a medical consultation, such as the sexually transmitted nature of the virus, may be cause of concern to them, while talking to women with similar diagnoses may bring some relief.

*“[...] the first thing I asked him [the physician] was about sexual relations. After the doctor saw me, yes, I got worried and complained to my husband.”* (Susana, 43)

*“Maybe I feel like: ‘Am I the only one having this?’ And then I say ‘No, there are thousands of us.’ Then, my cousin, who also had problems [...] one day we started talking and I realized I had experienced the same almost at the same time. We started to talk. It’s something we both share. She’s also dealing with this, under treatment, she’s having a colposcopy.”* (Leonor, 36)

### Discussion

In our study, we analysed perceived and unperceived information needs among HPV+ women. Our results indicated that women who get a positive screening have unmet information needs and need further information. In addition to the

health system, main sources of information consulted were close relatives, friends and the internet.

In particular, we found perceived information needs regarding HPV+ results and their meaning, the potential progression of the virus, the risk of cervical cancer, follow-up steps and information concerning sexual transmission. These results were similar to results reported in studies conducted in Belgium, Ireland, and England.<sup>13,22,27</sup> In Latin America, a qualitative study carried out in Mexico also reported that women who received the result for HPV tests needed further information about the meaning of such results, the steps to follow in care, and about the sexual transmission of HPV. In addition, both Mexican women and our interviewees showed interest in receiving information and emotional support.<sup>10</sup>

A central finding of our study relates to the unperceived information needs of women. Thus, although interviewed women did not necessarily perceive that they had not understood or they needed further information, analysing issues arising during the counselling part of the interview allowed us to identify information gaps related to key pieces of the prevention process. One main gap was related to information about biopsies and treatments. One study carried out in Belgium has also found fertility as an HPV information need but did not relate it to biopsy and treatment effects.<sup>13</sup> Other studies have pointed out the need for follow-up information but not specifically concerning biopsy and treatment.<sup>10,13</sup> This lack of information on biopsy and treatment and its impact on women's bodies and health is a key unperceived information need which may have important consequences for women's health. In our study, several women reported an unplanned pregnancy as they did not understand what the treatment entailed in relation to their fertility or use of contraception methods. Lack of knowledge about screening, diagnosis and HPV treatment may also result in low adherence to the follow up and treatment process, jeopardising the effectiveness of the screening strategy.<sup>32,33</sup> Therefore, it is very important to develop strategies to clearly communicate with women regarding diagnostic procedures and the treatment they received.

Similarly to other Latin American studies, our study showed that suspicion of infidelity is a

main concern for HPV positive women, although the lack of understanding of the timing of the sexual transmission of the virus was not perceived as an information need. Arellano Gálvez and Castro Vásquez, in their studies of HPV+ women found similar results.<sup>34,35</sup> This infidelity suspicion linked to the HPV result may have an impact on family and couple life, as well as a stigmatising connotation. Therefore, discussing the sexual transmission of the virus, as well as its relation with the current or past sexual activity of the couple, should be included in the information/counselling provided by the health system, aiming at dismantling the association between the sexual nature of transmission of the HPV infection and certain infidelity. Even though the risk of partner violence for HPV+ woman was not mentioned by our interviewees, a study carried out in Mexico showed that HPV+ women might experience partner violence for having a positive result.<sup>10</sup> According to the "Global strategy for the prevention and control of sexually transmitted infections" of the World Health Organization, the association with infidelity and the stigma of sexual transmitted infections may trigger violence against women.<sup>36</sup> Therefore, further research should focus on the risk of partner violence for HPV+ woman.

In line with our results, the evidence indicates that women receive information about HPV test and/or Pap smear results from several sources, such as the medical consultation, health workers, conversations with close relatives and the internet.<sup>22–24</sup> Additionally, it has been shown that understanding information and the resulting emotional relief it may cause is not necessarily related to the adequacy of the information.<sup>18,37</sup> In our research, uncertainty and concern regarding the HPV results were not related to the source of information, but to receiving appropriate explanations that were complete and understandable for the women and adapted to their specific diagnosis. Thus, finding other women with similar diagnoses, or information on the internet, may bring women some relief, while the information received in the medical consultation, such as the sexually transmitted nature of the virus, may concern them. However, information found on the internet or through close relatives may not be adequate or evidence-based. There is a risk that these sources of information may create more confusion or result in physical or psychological harm. Thus, it is important to complement information given during the consultation with the implementation



of strategies to provide women with evidence-based information through the channels they use (i.e. evidence-based web sites, mobile apps or community based strategies).

A limitation of this study is its protracted timeline, with women having received their HPV test results in 2013 and being interviewed in 2016. This could have had an impact on women's recall. However, all our interviewees reported clearly their experiences with HPV positivity and their HPV information needs, many of which were still present at the time of the interviews, three years later.

### Conclusions

Our results showed that women who get a positive HPV screening result have unresolved information needs, both perceived and unperceived, and need further information. The results highlight the need to create counselling strategies to encourage active listening to women so that they can express their feelings and concerns, even if they have trouble to put them into words. In addition, it is important to investigate why health professionals fail to deliver results with complete and clear information for women. Our results also indicate the need to work with health professionals to provide them with communication tools. Culturally adapted protocols to address women's information needs with tailor-made messages should be implemented. Devising strategies that incorporate the different sources consulted by women (such as internet pages or mobile phone apps that provide clear information) should also be considered. Finally, future qualitative and quantitative research may explore the intersectionality

between women's socio-economic characteristics (age, educational level, rural or urban residence) and their impacts on women's information needs.

### Disclosure statement

*No potential conflict of interest was reported by the author(s).*

### Funding

*This work was part of a subcomponent of the main project "Follow-up and treatment adherence for pre-cancerous lesions in the context of a cervical cancer prevention program based on the HPV test" led by Dr. Silvina Arrossi at Centro de Estudios de Estados y Sociedad (CEDES – Center of Studies of State and Society). It was funded by Agencia Nacional de Promoción Científica y Tecnológica (Scientific and Technological Promotion National Agency) and by Consejo Nacional de Investigaciones Científicas y Técnicas (CONICET – National Scientific and Technical Research Council), through the grant awarded to Lucila Szwarc. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Scientific and Technological Promotion National Agency.*

### ORCID

Lucila Szwarc  <http://orcid.org/0000-0003-4742-7696>

Victoria Sánchez Antelo  <http://orcid.org/0000-0003-4892-0394>

Melisa Paolino  <http://orcid.org/0000-0002-8649-1570>

Silvina Arrossi  <http://orcid.org/0000-0002-5071-0938>

### References

1. Wentzensen N, Arbyn M. HPV-based cervical cancer screening – facts, fiction, and misperceptions. *Prev Med.* 2017;98:33–35. DOI:10.1016/j.ypmed.2016.12.040
2. Arrossi S, Paolino M, Laudi R, et al. Programmatic human papillomavirus testing in cervical cancer prevention in the Jujuy demonstration project in Argentina: a population-based, before-and-after retrospective cohort study. *Lancet Glob Health.* 2019;7(6):e772–e783. DOI:10.1016/S2214-109X(19)30048-8
3. Tota JE, Bentley J, Blake J, et al. Introduction of molecular HPV testing as the primary technology in cervical cancer screening: acting on evidence to change the current paradigm. *Prev Med.* 2017;98:5–14. DOI:10.1016/j.ypmed.2016.11.029
4. Arrossi S, Laura T, Paul L. Prevención del cáncer cervicouterino: recomendaciones para el tamizaje, seguimiento y tratamiento de mujeres en el marco de programas de tamizaje basados en el test de VPH: actualización 2015. Ciudad Autónoma de Buenos Aires: Instituto Nacional del Cáncer; 2015.
5. Nicolas W, Schiffman Mark P, Timothy AM. Triage of HPV positive women in cervical cancer screening. *J Clin Virol.* 2016;76(Suppl 1):S49–S55. DOI:10.1016/j.jcv.2015.11.015

6. Arrossi S, Paolino M, Laudi R, et al. Programmatic human papillomavirus testing in cervical cancer prevention in the Jujuy demonstration project in Argentina: a population-based, before-and-after retrospective cohort study. *Lancet Glob Health*. 2019;7:e772–e783. DOI:10.1016/S2214-109X(19)30048-8
7. Torres-Ibarra L, Cuzick J, Lorincz AT, et al. Comparison of HPV-16 and HPV-18 genotyping and cytological testing as triage testing within human papillomavirus-based screening in Mexico. *JAMA Netw Open*. 2019;2(11):e1915781. DOI:10.1001/jamanetworkopen.2019.15781
8. Thangarajah F, Einzmann T, Bergauer F, et al. Cervical screening program and the psychological impact of an abnormal pap smear: a self-assessment questionnaire study of 590 patients. *Arch Gynecol Obstet*. 2016;293(2):391–398. DOI:10.1007/s00404-015-3821-z
9. Jentschke M, Lehmann R, Drews N, et al. Psychological distress in cervical cancer screening: results from a German online survey. *Arch Gynecol Obstet*. 2020;302(3):699–705. DOI:10.1007/s00404-020-05661-9
10. León-Maldonado L, Allen-Leigh B, Lazcano-Ponce E. Consejería en la detección de VPH como prueba de tamizaje de cáncer cervical: un estudio cualitativo sobre necesidades de mujeres de Michoacán, México. *Salud Pública de México*. 2014;56(5):519–527. DOI:10.21149/spm.v56i5.7377
11. McBride E, Marlow LAV, Forster AS, et al. Anxiety and distress following receipt of results from routine HPV primary testing in cervical screening: the psychological impact of primary screening (PIPS) study. *Int J Cancer*. 2020;146(8):2113–2121. DOI:10.1002/ijc.32540
12. O'Connor M, Costello L, Murphy J, et al. Influences on human papillomavirus (HPV)-related information needs among women having HPV tests for follow-up of abnormal cervical cytology. *J Fam Plann Reprod Health Care*. 2015;41(2):134–141. DOI:10.1136/jfprhc-2013-100750
13. Verhoeven V, Baay MFD, Baay PE, et al. Everything you always wanted to know about HPV (but could not ask your doctor). *Patient Educ Couns*. 2010;81(1):101–105. DOI:10.1016/j.pec.2009.12.006
14. Marván ML, Y Ehrenzweig, RL Catillo-López. Fatalistic beliefs and cervical cancer screening among Mexican women. *Health Care Women Int*. 2016;37(1):140–154. DOI:10.1080/07399332.2014.959169
15. Rask M, Swahnberg K, Lindell G, et al. Women's experiences of abnormal pap smear results – a qualitative study. *Sex Reprod Healthc*. 2017;12:3–8. DOI:10.1016/j.srhc.2017.01.002
16. Patel H, Moss EL, Sherman SM. HPV primary cervical screening in England: women's awareness and attitudes. *Psychooncology*. 2018;27(6):1559–1564. DOI:10.1002/pon.4694
17. Arrossi S, Almonte M, Herrero R, et al. Psycho-social impact of positive human papillomavirus testing in Jujuy, Argentina results from the Psycho-Estampa study. *Prev Med Rep*. 2020;18:101070. DOI:10.1016/j.pmedr.2020.101070
18. Vamos CA, Calvo AE, Daley EM, et al. Knowledge, behavioral, and sociocultural factors related to human papillomavirus infection and cervical cancer screening among inner-city women in Panama. *J Community Health*. 2015;40(6):1047–1056. DOI:10.1007/s10900-015-0030-4
19. Hsu Y-Y, Cheng Y-M, Hsu K-F, et al. Knowledge and beliefs about cervical cancer and human papillomavirus among Taiwanese undergraduate women. *Oncol Nurs Forum*. 2011;38(4):E297–E304. DOI:10.1188/11.ONF.E297-E304
20. Kahn JA, Slap GB, Bernstein DI, et al. Personal meaning of human papillomavirus and pap test results in adolescent and young adult women. *Health Psychol*. 2007;26(2):192–200. DOI:10.1037/0278-6133.26.2.192
21. Paolino M, Arrossi S. Análisis de los motivos del abandono del proceso de seguimiento y tratamiento por parte de mujeres con lesiones precursoras de cáncer de cuello uterino en la provincia de Jujuy: implicancias para la gestión. *Salud Colect*. 2012;8:247–261. DOI:10.1590/S1851-82652012000400003
22. Marlow L, Forster AS, McBride E, et al. Information needs among women taking part in primary HPV screening in England: a content analysis. *BMJ Open*. 2020;10(12):e044630. DOI:10.1136/bmjopen-2020-044630
23. Tiro JA, Betts AC, Kimbel K, et al. Understanding patients' perspectives and information needs following a positive home human papillomavirus self-sampling kit result. *J Womens Health*. 2019;28(3):384–392. DOI:10.1089/jwh.2018.7070
24. Liebermann EJ, VanDevanter N, Hammer MJ, et al. Social and cultural barriers to women's participation in pap smear screening programs in low- and middle-income Latin American and Caribbean countries: an integrative review. *J Transcult Nurs*. 2018;29(6):591–602. DOI:10.1177/1043659618755424
25. Lai D, Bodson J, Davis FA, et al. Diverse families' experiences with HPV vaccine information sources: a community-based participatory approach. *J Community Health*. 2017;42(2):400–412. DOI:10.1007/s10900-016-0269-4
26. Young A, Cotton S, Cruickshank ME. Information needs of young women vaccinated against HPV attending colposcopy: a qualitative study. *BMC Women's Health*. 2018;18(1):200. DOI:10.1186/s12905-018-0691-0
27. O'Connor M, Costello L, Murphy J, et al. "I don't care whether it's HPV or ABC, I just want to know if I have cancer." Factors influencing women's emotional responses to undergoing human papillomavirus testing in routine management in cervical screening: a qualitative study.

- BJOG: Int J Obstet Gynaecol. 2014;121(11):1421–1429. DOI:10.1111/1471-0528.12741
28. Arrossi S, Thouyaret L, Laudi R, et al. Implementation of HPV-testing for cervical cancer screening in programmatic contexts: the Jujuy demonstration project in Argentina: implementation of HPV testing as primary screening in Argentina. *Int J Cancer*. 2015;137(7):1709–1718. DOI:10.1002/ijc.29530
  29. Daher M, Carré D, Jaramillo A, et al. Experience and meaning in qualitative research: a conceptual review and a methodological device proposal. *Forum Qual Sozialforschung/Forum Qual Soc Res*. 2017;18(3):Art. 9. DOI:10.17169/fqs-18.3.2696
  30. Cuberli M, Arrossi S. Consejería para la prevención del cáncer de cuello de útero. Propuestas para una mejor comunicación con las mujeres durante el tamizaje, seguimiento y tratamiento. Buenos Aires: Instituto Nacional del Cáncer (INC); 2013.
  31. Strauss A, Corbin J. Bases de la investigación cualitativa. Técnicas y procedimientos para desarrollar la teoría fundamentada. Antioquia: Editorial Universidad de Antioquia; 1990.
  32. Sharpe PA, Brandt HM, McCree DH. Knowledge and beliefs about abnormal pap test results and HPV among women with high-risk HPV: results from in-depth interviews. *Women Health* 2006;42(2): 107–133.
  33. Schoenberg N, Baltisberger J, Bardach S, et al. Perspectives on pap test follow-up care among rural Appalachian women. *Women Health*. 2010;50(6):580–597. DOI:10.1080/03630242.2010.516702
  34. Gálvez A, del Carmen M, Vásquez C, et al. El estigma en mujeres diagnosticadas con VPH, displasia y cáncer cervicouterino en Hermosillo, Sonora. *Estud Soc*. 2013;21(42):259–278.
  35. Monsalve-Páez S, Valderrama-Vega D, Castillo-Zamora M, et al. Experiencia de las pacientes frente a citología cérvico-vaginal reportada como ASCUS o LEI de bajo grado en dos instituciones de Bogotá (Colombia), 2014. *Rev Colomb Obstet Ginecol*. 2015;66(1):14–21. DOI:10.18597/rcog.3
  36. World Health Organization. Global strategy for the prevention and control of sexually transmitted infections: 2006–2015. Breaking the chain of transmission. Geneva: World Health Organization; 2015. Available from: <http://www.who.int/reproductivehealth/publications/artis/9789241563475/en/index.html>
  37. McCree Hubbard D, Sharpe PA, Brandt HM, et al. Preferences for sources of information about abnormal pap tests and HPV in women tested for HPV. *Prev Med*. 2006;43(3):165–170. DOI:10.1016/j.yjmed.2006.04.001

## Résumé

L'objectif de cette étude qualitative était d'explorer les besoins d'information des femmes positives au virus du papillome humain (VPH). Nous avons réalisé 38 entretiens approfondis avec des femmes positives au VPH dans la province de Jujuy, Argentine. Les entretiens comprenaient une séance de consultation pour répondre aux préoccupations et questions des femmes. Les femmes ont estimé que les informations fournies étaient bonnes, même si elles avaient plusieurs doutes et idées erronées après avoir reçu les résultats d'un test de dépistage du VPH. Elles ont fait état de difficultés pour formuler des questions pendant la consultation en raison de sentiments de honte, de l'excès d'informations reçues ou du manque de familiarité avec le langage technique. Elles ont apprécié le soutien psychologique et la bienveillance avec laquelle elles avaient été traitées par les professionnels. Les besoins d'informations perçus étant apparus comme les plus importants étaient: (1) la signification d'un résultat de test de dépistage du VPH et sa relation avec une évolution en cancer du col de l'utérus

## Resumen

El objetivo de este estudio cualitativo era explorar las necesidades de información de mujeres HPV+. Realizamos 38 entrevistas a profundidad con mujeres HPV+ en la provincia de Jujuy, en Argentina. Las entrevistas incluían una sesión de consejería para responder a las preocupaciones y preguntas de las mujeres. Las mujeres percibieron la información proporcionada como buena, a pesar de tener varias dudas e ideas erróneas después de recibir resultados HPV+. Expresaron dificultades formulando preguntas durante la consulta por sentirse avergonzadas, por exceso de información proporcionada o por falta de familiaridad con los términos técnicos. Valoraron el apoyo emocional y recibir un trato amable de los profesionales. Las necesidades de información percibidas surgidas como las más importantes fueron: (1) el significado de un resultado HPV+ y su relación con la evolución y gravedad del cáncer cervical; (2) continuidad del proceso de atención y momento en que ocurre ese proceso; (3) información sobre la transmisión sexual del virus; (4) explicación de la presencia o ausencia de

et sa gravité; (2) la continuité et le calendrier du processus de soins; (3) l'information sur la transmission sexuelle du virus; (4) l'explication de la présence ou de l'absence de symptômes. Les principaux besoins en information non perçus des femmes étaient: (1) des informations détaillées sur la colposcopie, la biopsie et les traitements ainsi que leurs conséquences (y compris des effets sur la fécondité); et (2) la déconstruction de l'association entre transmission sexuelle et infidélité. Les sources d'information comprenaient: (1) le système de soins de santé; (2) internet; (3) des rencontres sociales (amis proches et parents). Il est capital de renforcer le processus de communication des résultats, avec des informations plus exhaustives, un meilleur soutien psychologique et une écoute active centrée sur la patiente, ainsi que de concevoir de nouvelles modalités pour fournir les informations par étapes et/ou progressivement, afin de faciliter l'accès des femmes au système de soins de santé et aux informations dont elles ont besoin.

síntomas. Las principales necesidades de información de las mujeres no percibidas fueron: (1) información detallada sobre la colposcopia, biopsia, y tratamientos y sus efectos (incluidas las consecuencias de la fertilidad); y (2) deconstrucción de la asociación de la transmisión sexual con la infidelidad. Fuentes de información incluidas: (1) el sistema de salud; (2) internet; y (3) encuentros sociales (amistades cercanas y parientes). Es imperativo fortalecer los procesos para dar resultados con información más completa, mejor apoyo emocional y escucha activa enfocada en la paciente, así como concebir nuevos formatos para proporcionar información en etapas y/o gradualmente, con el fin de facilitar el acceso de las mujeres al sistema de salud y a la información que necesitan.