

An online survey on emotions, impact on everyday life, and educational needs of women with HPV positivity or abnormal Pap smear result

Andrea Ciavattini, MD^{a,*}, Giovanni Delli Carpini, MD^a, Luca Giannella, MD^a, Anna Del Fabro, MD^b, Vivek Banerji, MBA^c, Genevieve Hall, B.Math^c, Maggiorino Barbero, MD^d, Francesco Sopracordevole, MD^b

Abstract

This study aimed to evaluate the emotional path, impact on everyday life, and adequacy of patient education throughout the diagnostic and therapeutic journey of women who received a positive human papillomavirus (HPV) test or Pap smear result.

An online survey was designed to determine the demographic characteristics, dominant feelings throughout the diagnostic and therapeutic procedures, major lifestyle changes, impact on social life, and perceived adequacy of patient information in Italian women with a positive HPV test or abnormal cervical cytology result. In this study, the phases of the “patient’s journey” included the initial test, waiting for colposcopy or biopsy, waiting for surgery, and follow-up.

Anxiety, worry, and fear were the most frequently cited emotions during the initial tests and intervals between procedures. Anxiety and fear gradually decreased during the journey until surgery, and higher levels of optimism were observed postsurgery. The most frequently reported lifestyle changes were attempts to boost the immune system, increased precautions in sexual practices, and dietary changes. Social life is affected by changes in sexual and intimate relationships with partners. Women reported receiving insufficient patient education on the diagnosis and its implications, progression, management, personal care, and resolution.

Significant attention should be given to the psychosocial aspects of the entire patient journey after receiving a positive HPV test or an abnormal Pap smear result. It is essential to establish a good rapport between patients and healthcare professionals, and to educate women regarding the condition by minimizing the gap between the perceived and desired adequacy of information.

Abbreviations: HPV = human papillomavirus, HR-HPV = high-risk human papillomavirus.

Keywords: colposcopy, emotional path, emotions, HPV test, information, pap smear, screening

1. Introduction

Cervical cancer is the fourth most common cancer affecting women, with an estimated incidence that exceeds 500,000 women worldwide yearly.^[1] Treatment regimens, including surgery and adjunctive chemoradiotherapy, are relatively effective in women with early-stage disease; however, their efficacy decreases substantially in advanced disease.^[2] In this regard, screening programs have been widely successful in reducing the mortality

rate from cervical cancer by identifying invasive cervical cancer in its early stages or dysplastic intraepithelial lesions before their progression to invasive carcinoma.^[3,4]

Infection by high-risk human papillomavirus (HR-HPV) is recognized as the causative factor of the vast majority of pre-invasive and invasive cancers of the female lower genital tract.^[5]

Both vaccination and screening for HR-HPV are used for primary and secondary prevention of cervical cancer.^[5,6]

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^a Gynecologic Section, Department of Odontostomatologic and Specialized Clinical Sciences, Università Politecnica delle Marche, Ancona, Italy, ^b Centro di Riferimento Oncologico di Aviano-IRCCS, SOC Chirurgia Oncologica Ginecologica, Aviano, Italy, ^c Insight Dojo, Studio 206, The Print Rooms, 164–180 Union Street, London, UK, ^d Azienda Sanitaria Locale di Asti, SOC Ostetricia e Ginecologia, Asti, Italy.

* Correspondence: Andrea Ciavattini, Gynecologic Section, Department of Odontostomatologic and Specialized Clinical Sciences, Università Politecnica delle Marche, Via F. Corridoni 11, 60123 Ancona, Italy (e-mail: ciavattini.a@libero.it).

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Current national and international guidelines recommend either HPV-based screening with cytologic triage of positive women or co-testing with cytology.^[7] However, previous studies have reported that HPV-based screening may require extensive patient education to advise women of the need for human papillomavirus (HPV) testing despite the absence of treatment for HPV infection.^[8]

Notwithstanding its indisputable benefits, potential pitfalls of cervical cancer screening have been identified by some authors, specifically, the perceived risk of cervical cancer and the impact of an abnormal result on psychological states.^[9] It has been reported that more than half of women who received an abnormal screening result may experience psychological distress and anxiety,^[10,11] which could last for up to 2 years in women who were referred for colposcopy.^[12] In general, women do not expect to receive abnormal results. Thus, the sudden news generates fear of cancer, self-disappointment and sexual anxiety,^[13–15] infertility concerns, self-blame, low self-esteem, and feelings of contamination.^[16,17] These negative emotions may be caused by difficulties in discerning the actual impact of HPV positivity while awaiting results, procedures, or follow-up appointments.^[18,19]

However, there has been no thorough analysis on the range of emotional states of women, following an abnormal cervical cancer screening test result. Such information is essential in identifying the educational needs of women during the entire diagnostic and therapeutic journey.^[20]

Therefore, to obtain greater insight into these aspects, we performed an extensive online-based survey in Italy for the assessment of real-life experiences among women with an abnormal HPV test or Pap smear result (i.e., first-level test). The main goal was to identify their responses to information and follow them throughout the subsequent phases of their journey as a patient. Data were collected on dominant feelings, lifestyle changes, impact on social and sexual life, and perceived adequacy of the patient information.

2. Methods

2.1. Study design and participants

A quantitative research with an online survey, designed by Insight Dojo (United Kingdom) and approved by a pool of board members (AC, MB, and FS) of the Italian Society of Colposcopy and Cervical Vaginal Pathology, was performed. The survey (in Italian) was administered to Italian women from an online consumer panel that is representative of the general population, and only women with a positive HPV test or abnormal cervical cytology result constituted the final study population.

The primary outcome measured was the percentage of the most dominant feeling at the time of receiving the test result.

A 2-step approach was used to define the final study sample. Participants were sourced from an active internet panel composed of more than 150,000 Italian women who had expressed general willingness to participate in the surveys.

Prior to the administration of the survey to the general Italian female population, an invitation was first sent to a nationally representative sample of 1115 women in our online panel. This aimed to obtain a preliminary quantification of the percentage of women with a positive HPV test result or abnormal cervical cytology in the previous year and to establish an age profile of women to target for participation in the next stage. Among the 1115 participants in the first phase, 88 (7.9%) reported receiving

a positive HPV test or abnormal Pap smear result in the previous 12 months, with an age range of 21 to 65 years. Two interviews were conducted with these women for the validation of the questionnaire and the assessment of the most dominant feeling reported at the time of the initial test, which served as the primary study outcome.

The total number of women in Italy aged 21 to 65 years on January 1, 2017, was 18,182,344.^[21] Considering that an estimated 7.9% had a positive HPV test result or cervical cytology within the previous year, our general reference population consisted of approximately 1,436,405 women. To provide an adequate sample size for the present survey, a study population of at least 971 women was needed, considering a percentage of 35% set for the primary outcome, a confidence level of 95%, and a confidence interval of 3%.

Based on the information above, we subsequently invited the entire panel of 150,000 women, representative of the general population, to participate in the second phase of the survey. Among them, 15,090 (10.1%) women submitted responses. The 1003 (6.7%) who reported a positive HPV test result or cervical cytology in the past year were then allowed to complete the entire questionnaire and were included in the final analysis.

The online questionnaire for the second phase was made available from July 27 to August 21, 2018. Participants were allowed access to the questionnaire after providing informed consent.

2.2. Questionnaire and outcomes

The questionnaire was structured around the entire diagnostic and therapeutic procedures, including the intervals between them, designated as the phases in the “patient’s journey.” The phases investigated included the following: initial test (i.e., having the initial test, awaiting initial results, receiving initial results, and after receiving results); waiting time for colposcopy or biopsy; colposcopy or biopsy (i.e., waiting on the day of the procedure, awaiting results, and receiving results); waiting time for surgical procedure; surgery (i.e., waiting on the day of the surgery, from pre- to postoperation); follow-up, including the waiting time for the next appointment; and daily life postsurgery.

The data collected were the following: demographic characteristics; dominant feelings throughout the patient’s journey; main lifestyle changes; impact on social life; and perceived adequacy of the information. The full questionnaire is available as supplementary material (Supplemental Digital Content 1, <http://links.lww.com/MD/G475>).

2.2.1. Demographic characteristics. The demographic characteristics at the time of the initial test, including the age, educational qualification, job status, relationship status, and frequency of sexual intercourse, were recorded.

2.2.2. Dominant feelings throughout the patient’s journey. The percentage of women who reported anxiety, worry, fear, terror, optimism, placidity, nervousness, or panic during each phase of the patient’s journey was recorded.

2.2.3. Main lifestyle changes. The specific outcome was the percentage of women who reported making at least one of the following main lifestyle changes during each phase of the patient’s journey: stopped having sexual intercourse or decreased its frequency; quit or reduced smoking or drinking alcohol; discontinued sharing towels/bedding with others;

notified their sexual partners; changed their personal household habits to avoid transmission of infection; changed towels/bedding more regularly; increased their physical activity; made dietary changes; started taking precautionary measures regarding their sex life; or attempted to boost their immune system.

2.2.4. Impact on social life. To assess the impact on social life, the specific outcome was the percentage of women who reported making changes in at least one of the following aspects during each phase of the patient's journey: sexual relationships; intimate relationships; relationships with family and friends; work habits; hobbies and travel; and sleeping pattern or quality of sleep.

2.2.5. Perceived adequacy of patient information. Perceived adequacy of patient information was defined as the comparison between the desired level of information and the actual level of information provided by the health practitioner, as reported by the study participants after the results of the initial test, colposcopy or biopsy, and surgery. The adequacy of information was assessed according to the extent of explanation on the following: diagnosis after the initial test and colposcopy or biopsy; the etiology and pathophysiology of the condition; the implications of the condition and reassurance for the individual; further tests and procedures; disease progression; personal care and products for use in management; necessary lifestyle changes; and digital resources such as colposcopy, biopsy, or surgery videos to demonstrate either active or resolved HPV infection, dysplastic lesions, or cervical carcinoma.

Data were collected and entered in Microsoft Excel (Microsoft Office Professional Plus, 2013). Descriptive statistics reporting the numbers and percentages of each measured outcome were used to present the data. The study was conducted in accordance with the principles of the World Medical Association Declaration of Helsinki.

3. Results

Among 15,090 women from the general population who responded to the survey during the study period, 1003 (6.7%) women with a positive HPV test or abnormal Pap smear result in the previous year were included in the final analysis. A total of 570 (56.8%) women had undergone an HPV test, 873 (87.0%) had a Pap smear, and 440 (43.9%) had co-testing with HPV test and Pap smear. There were 120 (12.0%) women who were sent to follow-up without a colposcopy or biopsy, 432 (43.1%) who were sent to follow-up after colposcopy or biopsy without surgery, and the remaining 451 (45.0%) who reported having surgery after colposcopy/surgery. The reported outcomes were expressed according to the total number of patients in each phase.

3.1. Demographic characteristics

The demographic characteristics of the study participants are presented in Table 1. The largest age group comprised women aged 36 to 40 years (23%). The vast majority had either a secondary school diploma or university degree (76%), and were employed full-time (73%).

3.2. Emotions throughout the patient journey

Dominant emotions at different stages of the patient journey are shown in Figure 1.

Table 1

Demographic characteristics of participants.

Characteristic	Study population (n = 1003)
Age	
21–25 yrs	80 (8)
26–30 yrs	112 (11)
31–35 yrs	158 (16)
36–40 yrs	234 (23)
41–45 yrs	166 (17)
46–50 yrs	143 (14)
51–55 yrs	76 (8)
56–60 yrs	27 (3)
61–65 yrs	7 (1)
Educational qualification	
Primary school	72 (7)
Secondary school	384 (38)
University	381 (38)
Doctoral degree (PhD)	68 (7)
Professional degree (MD, JD)	98 (10)
Job status	
Working full time	734 (73)
Self employed	98 (10)
Unemployed	123 (12)
Student or in full time training	39 (4)
Retired/semi-retired	9 (1)
Relationship status	
Single	201 (20)
Married	584 (58)
In a relationship	218 (22)
Frequency of sexual intercourse at the moment of initial test result	
Every day	51 (5)
At least once in a week but not everyday	526 (52)
Between once a week and once a month	194 (19)
Less often	232 (23)

Data are reported as n (%).

Anxiety was the most frequently cited emotion (37% and 35% during the initial test and initial result, respectively), followed by worry (31% and 26% upon receiving and after receiving initial results, respectively), and fear (28% and 26% during the initial test and initial result, respectively).

The proportion of women with emotional distress (e.g., anxiety and worry) was higher during the initial test period and during waiting intervals than in other phases. Thus, waiting for the initial test or subsequent procedures was identified as distressing. Anxiety and fear showed decreasing proportions approaching surgery, and while worry persisted, its proportions dropped significantly postoperatively (17%). Moreover, a high level of anxiety was observed during the waiting time for colposcopy or biopsy results (28%), showing a similar value during the start of the surgical phase (27%). A higher level of optimism (23%) was observed postsurgery than in other phases. When the participants were asked about emotions present on daily recollection of their overall experience, worry (26%), anxiety (21%), and fear (18%) were cited. Table 2 reports the most dominant feelings throughout the patient's journey, grouped according to the demographic characteristics of the participants. Women aged 26 to 30 years presented the higher prevalence of anxiety during initial test and colposcopy/biopsy, and of worry during surgery. Women aged 21 to 25 years and 56 to 60 years were the most hopeful during wait and see. Women with secondary school qualification were the most worried

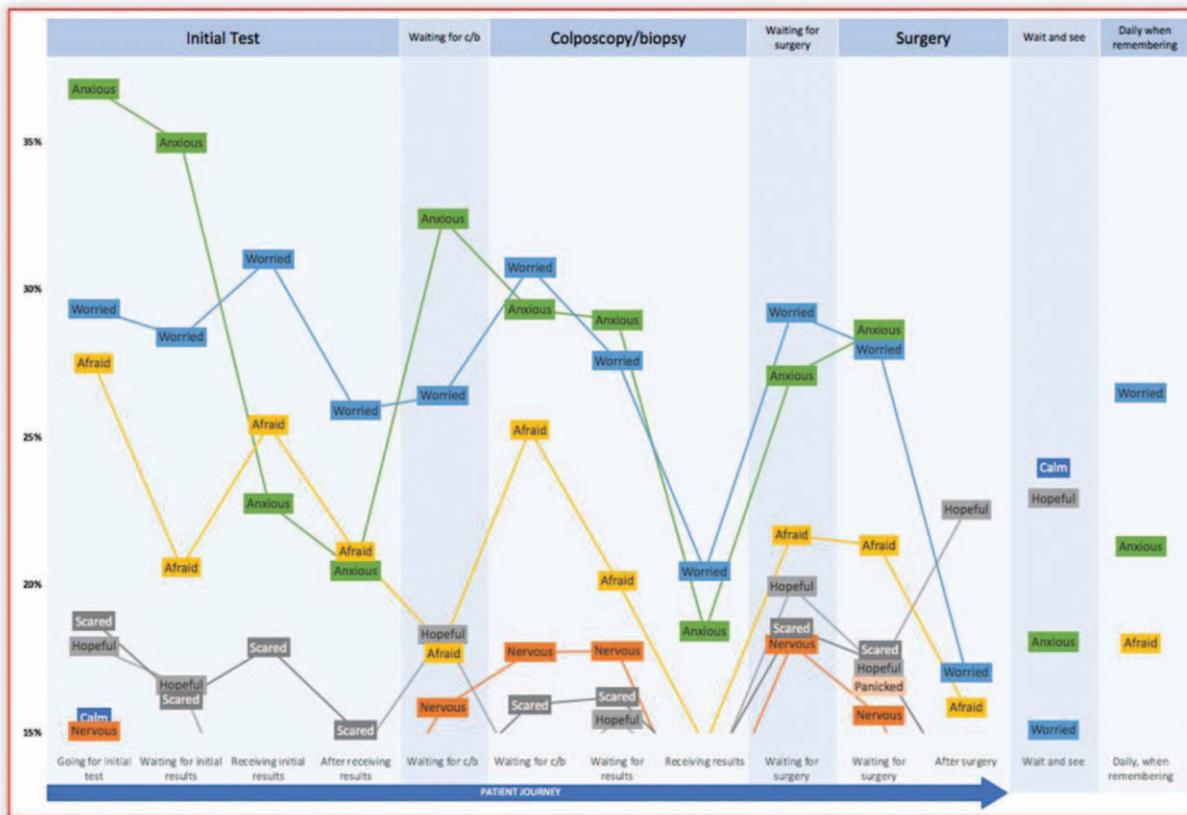


Figure 1. Dominant feelings throughout the patient's journey.

during colposcopy/biopsy. Single women were the most worried during colposcopy/biopsy, while married women were the most anxious during surgery. No difference according to the type of initial test were noted.

3.3. Changes in lifestyle after diagnosis

The main lifestyle changes after the diagnosis are presented in Table 3. Among the most frequently cited were attempts to boost the immune system (29%), increased precautions in sexual practices (22%), and dietary changes (18%). The percentages of women making lifestyle changes were consistent throughout all phases of the patient's journey.

3.4. Impact on social life

The impact on social life is shown in Table 4. Most changes were cited in sexual relationships (19%–23%) and intimate relationships (15%–19%). Approximately 1 in 6 women indicated that they had sleeping difficulties. The social impact was consistent throughout the various phases of the patient's journey, although observed in a lesser degree during waiting for the next follow-up appointment.

3.5. Adequacy of the information received, as perceived by women

The perceived adequacy of information received was low after receiving the initial test results (Table 5). The most significant

gaps between desired and actual level of information received were found in the explanation of the diagnosis (38% vs 31%, respectively) and the implications for the patient (36% vs 22%, respectively). Women reported needing more information on disease progression and on personal care and management (29% vs 21% and 29% vs 16%, respectively, for desired vs actual level of information received).

There were also perceived gaps in the information provided regarding colposcopy or biopsy results, as shown in Table 5. In particular, women wanted more information on disease progression, on whether the condition has resolved or not, and on measures they could personally take to aid in management (24% vs 18%; 22% vs 17%; and 20% vs 15%, respectively, for desired vs actual level of information received).

A higher percentage of adequacy of information was noted after surgery (Table 5). The detected gaps between desired and actual level of information were as follows: 25% vs 20% for reassurance regarding the condition, 20% vs 16% for disease progression, and 17% vs 13% for HPV status or resolution.

4. Discussion

The results of this study indicate that the most reported emotions throughout the patient's journey were anxiety, worry, and fear. These emotions remained well-represented across all phases, particularly during waiting intervals, then dropped after the last phase, wherein placidity and optimism were more frequently reported. Therefore, receiving a positive HPV test or abnormal Pap smear result appears to have a significant impact on

Table 2
Most dominant feeling throughout patient’s journey according to demographic characteristics of participants.

Characteristic	N	Patient’s journey			
		Initial test	Colposcopy/biopsy	Surgery	Wait and see
Age					
21–25 yrs	80	Anxiety (30%)	Anxiety (23%)	Anxiety (24%)	Hope (40%)
26–30 yrs	112	Anxiety (41%)	Anxiety (35%)	Worry (41%)	Hope (26%)
31–35 yrs	158	Fear (23%)	Anxiety (27%)	Anxiety (27%)	Calm (15%)
36–40 yrs	234	Anxiety (21%)	Anxiety (38%)	Worry (30%)	Calm (22%)
41–45 yrs	166	Anxiety (31%)	Anxiety (22%)	Anxiety (33%)	Calm (40%)
46–50 yrs	143	Anxiety (31%)	Anxiety (30%)	Anxiety (30%)	Hope (22%)
51–55 yrs	76	Anxiety (34%)	Anxiety (33%)	Anxiety (37%)	Hope (20%)
56–60 yrs	27	Worry (26%)	Worry (34%)	Worry (50%)	Hope (45%)
61–65 yrs	7	Worry (29%)	Worry (33%)	Anxiety (60%)	Calm (27%)
	<i>P</i>	.01	.04	.03	<.01
Educational qualification					
Primary school	72	Anxiety (32%)	Worry (36%)	Anxiety (42%)	Calm (24%)
Secondary school	384	Worry (24%)	Worry (42%)	Anxiety (31%)	Calm (3%)
University	381	Anxiety (25%)	Anxiety (28%)	Worry (30%)	Hope (24%)
Doctoral degree (PhD)	68	Anxiety (23%)	Anxiety (28%)	Worry (25%)	Calm (12%)
Professional degree (MD, JD . . .)	98	Fear (26%)	Anxiety (28%)	Anxiety (22%)	Calm (30%)
	<i>P</i>	.71	<.01	.08	<.01
Job status					
Working full time	734	Anxiety (23%)	Anxiety (29%)	Worry (25%)	Hope (22%)
Self employed	98	Anxiety (32%)	Anxiety (33%)	Anxiety (42%)	Hope (37%)
Unemployed	123	Anxiety (27%)	Worry (38%)	Worry (39%)	Calm (23%)
Student or in full time training	39	Anxiety (30%)	Worry (35%)	Anxiety (39%)	Calm (25%)
Retired/semi-retired	9	Anxiety (36%)	Anxiety (37%)	Worry (43%)	Hope (32%)
	<i>P</i>	.28	.30	<.01	<.01
Relationship status					
Single	201	Worry (20%)	Worry (43%)	Worry (30%)	Calm (25%)
Married	584	Anxiety (27%)	Anxiety (29%)	Anxiety (42%)	Calm (23%)
In a relationship	218	Anxiety (29%)	Worry (36%)	Anxiety (38%)	Hope (26%)
	<i>P</i>	.08	<.01	<.01	.61
Frequency of sexual intercourse at the moment of initial test result					
Every day	51	Anxiety (25%)	Anxiety (23%)	Anxiety (22%)	Hope (17%)
At least once in a week but not everyday	526	Anxiety (28%)	Anxiety (35%)	Anxiety (30%)	Calm (23%)
Between once a week and once a month	194	Anxiety (32%)	Anxiety (28%)	Anxiety (25%)	Hope (36%)
Less often	232	Anxiety (40%)	Worry (33%)	Worry (25%)	Calm (34%)
	<i>P</i>	<.01	.15	.28	<.01
First level test					
HPV positivity only	570	Anxiety (35%)	Anxiety (31%)	Anxiety (26%)	Hope (31%)
Abnormal pap smear only	873	Anxiety (32%)	Worry (35%)	Worry (23%)	Calm (30%)
	<i>P</i>	.24	.13	.22	.72

Data are reported as n (%); chi-squared test was used as appropriate.
 HPV = human papillomavirus.

Table 3
Main lifestyle changes during the “patient’s journey”.

Lifestyle change	Since initial test	After the colposcopy/biopsy	After surgery	After receiving your results	Follow-up
Stopped having sex altogether	7%	8%	11%	9%	3%
Stopped/cut down on smoking or drinking alcohol	9%	11%	10%	10%	4%
Stopped/cut down on smoking	13%	13%	12%	11%	7%
Stopped sharing towels/bedding with others	14%	11%	15%	14%	6%
Stopped having as much sex	15%	13%	14%	14%	8%
Notified my sexual partners	15%	15%	13%	16%	8%
Changed my habits around the house to ensure that I do not pass the infection on	13%	15%	13%	15%	10%
Changed towels/bedding more regularly	16%	13%	13%	16%	10%
Increased my level of exercise	16%	14%	18%	13%	10%
Made changes to my diet	17%	17%	15%	16%	15%
Started taking more precautions in my sex life	23%	20%	18%	24%	13%
Attempted to boost my immune system	29%	28%	24%	30%	23%

Table 4
Impact on social life throughout the patient's journey.

Aspect of social life	Since initial test	After the colposcopy/biopsy	After surgery	After receiving your results	Follow-up
Sexual relationships	21%	22%	23%	19%	10%
Relationships with partners	17%	17%	19%	15%	8%
Sleeping pattern or quality of sleep	16%	10%	15%	13%	7%
Work	11%	10%	13%	9%	6%
Hobbies	12%	10%	13%	9%	5%
Relationships with family	13%	10%	11%	9%	5%
Travels	12%	10%	12%	9%	4%
Relationship with friends	12%	9%	11%	8%	5%

women's lifestyle, habits, and social life. There were determined attempts to boost the immune system, increased precautions in sexual practices, dietary changes, and changes in sexual and intimate relationships. While relying on the care of health professionals, women reported to receive less information than they would prefer regarding the explanation of their diagnosis and its implications, disease progression, personal care and management, and disease activity or resolution.

The emotions documented throughout the patient's journey were similarly reported in previous studies. For instance, a survey in Norway with more than 3500 female participants found that anxiety was the dominant emotion, and that 39% to 42% of women were either quite worried or very worried, with no differences in anxiety over primary cytology-based screening and primary HPV-based screening.^[22] Based on 52 in-depth interviews, another study revealed emotions such as stigma, fear, self-blame, powerlessness, and anger, which further highlighted the role of healthcare providers in considering and managing the emotional aspects associated with receiving a positive HPV test result.^[23]

Incidentally, women who were aware of HPV positivity were observed to have more significant concerns about test results, a higher perceived risk of cervical cancer, and a lower quality of life than women who were unaware of HPV.^[24] Other studies have documented that HPV positivity may increase worry over an abnormal Pap smear result and may even provoke shame in some women.^[25] The authors emphasized that healthcare providers should ensure provision of unequivocal and sufficient information to reduce unnecessary anxiety. However, it should

be considered that the anxiety generated by an abnormal test result may be from their personal conviction of having cancer, underlining the need for emotional support and education throughout the patient's journey.^[26]

In this study, the most frequently reported lifestyle change upon receiving the diagnosis was an attempt to boost the immune system, reported by nearly one-third of the women. To our knowledge, this is a novel finding. The attempts to boost the immune system were not specified or characterized in the survey; however, the assumptions include HPV vaccination. Therefore, HPV vaccination may be of considerable importance to patients, and healthcare professionals must be ready to administer the vaccine when needed.

After the diagnosis, feelings of worry and anxiety persisted in more than 20% of women. Given the high proportion of women reporting negative emotions, social life was expectedly affected by the diagnosis throughout the various phases of the patient's journey. Moreover, at the initial phases, several women disclosed that their desired level of information was not adequately met. This finding is supported by a survey which included women from Spain, France, and Portugal, who expressed a strong desire for more information from healthcare providers regarding cervical cancer and other HPV-related diseases.^[27] Additionally, the previous study documented that partners assumed a vital role in providing psychological support and that an abnormal Pap smear result had minimal impact on relationships with family and partners. In this study, however, sexual relationships were most affected, followed by intimate relationships and work.

Table 5
Perceived adequacy of information throughout the patient's journey.

	After initial test results		Following colposcopy/biopsy		Following surgery	
	Information wanted	Information given	Information wanted	Information given	Information wanted	Information given
Explanation of diagnosis	38%	31%	28%	28%	18%	24%
Reassurance about the condition and what it means for the woman	36%	22%	24%	19%	25%	20%
Information on further tests/procedures	33%	32%	20%	22%	17%	23%
Information on how the condition can progress	29%	21%	24%	18%	20%	16%
Information on a specific product that could help	21%	13%	18%	18%	14%	15%
Information on things that could be done to help	29%	16%	20%	15%	14%	15%
Information about changes that can/should be made to lifestyle	19%	13%	16%	13%	15%	15%
Information about the biology and physiology of the condition	18%	13%	14%	13%	14%	18%
Information about how the condition is acquired/caught	17%	17%	13%	13%	15%	13%
Explanation whether they were "cured" or not	NA	NA	22%	17%	21%	23%
Explanation whether they still had lesions or not	NA	NA	18%	20%	17%	20%
Explanation whether they still had HPV or not	NA	NA	17%	15%	17%	13%

HPV = human papillomavirus, NA = not applicable.

Nevertheless, our survey revealed that there were broad gaps in the information received by women throughout the entire diagnostic and therapeutic journey, and not limited to the diagnosis. As previously noted in the literature, it is necessary to improve patient knowledge regarding HPV through dissemination of public health messages and detailed educational programs regarding the disease.^[24] Healthcare providers should be aware of the importance of improved understanding of the condition on the psychosocial state and overall quality of life of the patient. Better education may also positively impact patient willingness to undergo additional screening. Papa et al^[28] reported that educational intervention diminished concerns about a positive HR-HPV result. Following an educational intervention, only 27% of referred women remained very concerned, compared to 60% prior to the intervention.

In a study on patient perspectives and needs for HPV self-sampling kits, it was concluded that education should ideally be provided at multiple points throughout the screening process.^[29]

Our results confirm that information is perceived as inadequate in all phases of the patient's journey. The lack of accurate knowledge may be a significant contributor to the myriad of negative emotions experienced after receiving an abnormal test result, which is likely to persist until the last phase.^[23] Other authors suggested that the information provided may be tailored to the specific setting and country.^[27] Considering the present-day reliance on the internet as a source of information, it may be utilized by healthcare providers by recommending accurate online sources that the patients can visit. It must be noted that giving precise information is critical due to the rampant incorrect and inappropriate information online.

Information and counseling are important in the management of patients with a positive HPV test or Pap smear result. More specifically, providing accurate information and verifying patient understanding are invaluable in the current clinical practice, wherein conservative management is increasingly recommended for low-grade lesions. Therefore, proactive participation of patients during follow-up is required. Moreover, the interaction with the colposcopist and the findings are relevant for the determination of the patient's individual risk, which, according to the recent American Society of Colposcopy and Cervical Pathology guidelines, defines the entire course of treatment and follow-up.^[30]

The strengths of the present study include the large study population, which was determined and selected with a robust methodology. Furthermore, the questionnaire was specifically designed to assess all phases of the patient's clinical journey after an HPV test or Pap smear positivity, which involved several contacts with healthcare facilities, ranging from a completely reassuring condition to a potentially invasive lesion. The main limitation of the study is that clinical data were self-reported and thus cannot be verified, considering that the study participants were not managed at our institution. However, the aim of the study was not purely clinical and involved the patient's emotional path, which could only be assessed through a questionnaire to be filled in by the patients themselves. The survey answer rate of 10.1% should be addressed as an additional limitation; however, the large number of women composing the online panel allowed us to include 1003 women with a positive HPV test or Pap smear in the past year, which satisfied the minimum number of included subjects according to the sample size calculation.

The results may be used to improve communication and disseminate adequate information to women during their clinical journey, from initial test results to colposcopy or biopsy to

surgery, if indicated. A focus on the psychosocial aspect is important in the post-HPV vaccination era for counseling regarding the indications of HPV vaccination and the occurrence HPV-related diseases in vaccinated individuals.^[31] In these cases, patients may have an excessive sense of security and HPV protection, resulting in decreased adherence to screening practices and an increased likelihood of a more substantial emotional crisis after HPV positivity.^[32,33]

In conclusion, the data from this extensive survey of Italian women highlighted that considerable attention should be focused on the psychosocial aspects of the patient's clinical journey, from receiving the results of the initial screening until after follow-up. To achieve this, it is essential to establish a good rapport between patients and healthcare professionals and to provide women with adequate information regarding the condition. Finally, it is necessary to minimize the gap between the level of information received and desired.

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Author contributions

Conceptualization: Andrea Ciavattini, Giovanni Delli Carpini, Maggiorino Barbero, Francesco Sopracordevole.

Data curation: Vivek Banerji, Genevieve Hall.

Formal analysis: Andrea Ciavattini, Giovanni Delli Carpini, Luca Giannella, Anna Del Fabro.

Investigation: Vivek Banerji, Genevieve Hall.

Methodology: Giovanni Delli Carpini, Luca Giannella, Anna Del Fabro, Vivek Banerji, Genevieve Hall.

Supervision: Andrea Ciavattini, Maggiorino Barbero, Francesco Sopracordevole.

Writing - original draft: Giovanni Delli Carpini, Luca Giannella, Anna Del Fabro.

Writing - review & editing: Andrea Ciavattini, Maggiorino Barbero, Francesco Sopracordevole.

Correction

When originally published, the funder for this article incorrectly appeared as Shionogi srl. It has been corrected to Procure Health, SL.

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