Analysis of the reasons for abandoning the follow-up and treatment process in women with pre-cancerous cervical lesions in the province of Jujuy: implications for health management

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

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ABSTRACT Adequate follow-up and treatment of women with high-grade squamous intraepithelial lesion (HSIL) and cancer is key in reducing cervical cancer mortality. This research study aims to analyze the magnitude of abandonment in the follow-up and treatment process, as well as the reasons for this abandonment, in women with HSIL who received care in public health services in the province of Jujuy in 2010. Secondary sources were analyzed and women were interviewed in their homes. The abandonment rate within the study population was 23.5%. Among these women, 40.5% mentioned organizational problems in the health care system as a reason for abandoning and 30.9% mentioned subjective reasons. Our results have been used in the reorganization of the follow-up and treatment process being carried out in the province.
KEY WORDS Uterine Cervical Neoplasms; Papanicolaou Smear; Cervix Neoplasm Prevention; Patient Dropouts; Argentina.

RESUMEN El adecuado seguimiento y tratamiento de las mujeres con lesiones escamosas intraepiteliales de alto grado (HSIL, por sus siglas en ingles) y carcinoma es un aspecto clave para la reducción de la mortalidad por cáncer de cuello uterino. El objetivo de esta investigación es analizar la magnitud y los motivos del abandono en el proceso de seguimiento y tratamiento por parte de las mujeres con diagnóstico de HSIL y carcinoma atendidas en el sistema público de la provincia de Jujuy durante 2010. Se realizó el análisis de fuentes secundarias y entrevistas domiciliarias a las mujeres. El porcentaje de abandono en la población de estudio fue del 23,5%. Entre estas mujeres, el 40,5% mencionó motivos de abandono relacionados con la organización del sistema de salud y el 30,9% mencionó motivos subjetivos. Los resultados han sido utilizados como insumos para la reorganización del proceso de seguimiento y tratamiento que se está llevando a cabo en la provincia.
PALABRAS CLAVES Neoplasias del Cuello Uterino; Papanicolaou; Prevención de Cáncer de Cuello Uterino; Desistencia al Tratamiento; Argentina.

INTRODUCTION

Cervical cancer is one of the few types of cancer that can be prevented with the technologies currently available. It has been proven that the Papanicolaou (Pap) smear, used in the framework of organized prevention programs (a), has reduced cervical cancer mortality rates by 80% (1). In recent years, the discovery of the causal association between human papillomavirus (HPV) and cervical cancer (2,3) has allowed for the development of new technologies (the HPV-DNA test and the HPV vaccine) which have opened up new perspectives for prevention. Indeed, the greater sensitivity and greater negative predictive value of the HPV test as compared to the cytology reduce the number of screenings that a woman must undergo (4-6).

However, technological development does not in itself reduce disease incidence and mortality due to this tumor, which mainly affects poor women with lower educational levels and less access to health services (7,8). In Argentina during the year 2010, approximately 1,800 women died of cervical cancer; the age-standardized mortality rate (ASMR) was 7 per 100,000 women (9). Furthermore, the mortality distribution in the country is extremely unequal: the ASMRs of the poorest provinces such as Misiones (17 per 100,000) or Jujuy (12 per 100,000) are 3 or 4 times higher than the ASMR of the city of Buenos Aires (4 per 100,000), the wealthiest region in the country (9). High mortality is related to problems in the continuity of the prevention process, in which the screening test is just a technological component. Indeed, the cervical cancer prevention process is made up of four essential stages: screening (b), via the Pap smear, HPV test, etc.; diagnosis, via biopsy, etc.; treatment, via the Loop Electrosurgical Excision Procedure (LEEP) (c); and follow-up after the treatment.

The stages following the screening are essential to the prevention of this disease. A research study carried out in Colombia showed that appropriate follow-up and treatment have more impact on reducing mortality than high screening coverage: the follow-up and treatment of 50% of the population with pre-cancerous cervical lesions in a context of 100% screening coverage can reduce the mortality risk up to

50%, while 100% follow-up and treatment in a context of 50% screening coverage may reduce the risk up to 70% (10).

Despite the importance of cervical cancer prevention, in Argentina there is an enormous lack of information regarding the magnitude of abandonment in the follow-up and treatment process and its underlying explanatory factors. An assessment report of the National Cervical Cancer Prevention Program and of the Argentine provincial programs, carried out in 2007-2008 (11), demonstrated that most of the provincial programs did not have records of how many women with pre-cancerous cervical lesions have continued with the follow-up and treatment process. Similarly, in most health care centers it was also not possible to obtain such information as it was not information that was systematically recorded. An absence of records was also observed in the health care services of a municipality in Greater Buenos Aires (12). The only precedent in Argentina is a research study carried out in the late 1980s in four hospitals of the province of Buenos Aires (13), which demonstrated that 40% of the women with abnormal cytology interviewed had abandoned all treatment actions related to their disease.

In order to explore these uncharted areas, since 2010 our team has developed different research studies (d) in Greater Buenos Aires and in selected provinces, with the main objective of analyzing the magnitude of abandonment and the socioeconomic, institutional and symbolic dimensions influencing the follow-up and treatment process of women with high-grade squamous intraepithelial lesions (HSIL) and carcinoma. As part of this broader project, between November 2010 and July 2011, a research study was carried out in the province of Jujuy with the following objectives:

1. To describe the magnitude of abandonment in the follow-up and treatment process of women with HSIL and carcinoma;
2. To analyze the socioeconomic characteristics of the women and the relationship of these characteristics to the abandonment of the health care process;
3. To identify the reasons for abandoning the care process;

4. To analyze the quality of delivery of the Pap smear results from the women's perspective and its relationship to abandonment of the health care process;

5. Develop a joint proposal with the local health care providers to strengthen the follow-up and treatment process of women with HSIL and carcinoma.

During the project, work was carried out in conjunction with the local health care providers: the Provincial Cervical and Breast Cancer Prevention and Control Program [*Programa Provincial de Prevención y Control de Cáncer de Cuello Uterino y Cáncer de Mamas*], the Provincial Direction of Primary Health Care and Community Action [*Dirección Provincial de APS y Acción Comunitaria*], and the Pathology and Gynecological services of the provincial hospital of reference. This collaboration was carried out not only to access to the information available, but also to facilitate the application of the research results and to contribute to the improvement of health care processes. The project was developed with the support of the National Cervical Cancer Prevention Program [*Programa Nacional de Prevención de Cáncer Cérvico-uterino]* and the Provincial Cervical and Breast Cancer Prevention and Control Program of the province of Jujuy, and was financed by the Pan American Health Organization (PAHO).

In this article we present the results of this project, which to our knowledge is the first research study regarding the magnitude of and reasons behind the abandonment of the follow-up and treatment process in women with HSIL and carcinoma who received care in any of the public health care providers in the province of Jujuy. The results have been used to inform the reorganization of the referral and counter-referral system being undertaken in that province.

METHODOLOGY

Setting in which the study was conducted

The province of Jujuy was selected because it is one of the provinces of greatest priority to the National Program given its high mortality rate. The project also had the support of the provincial authorities, who requested information that would allow them to measure the extent of the problem and establish solutions to solve it.

The public health care system of the province of Jujuy has approximately 250 Primary Health Care Centers (PHCC) where the Pap smear (e) is performed, four cytology laboratories, a pathology service of reference, nine diagnostic centers where colposcopies and biopsies are performed, and five services where the treatment is carried out. The screening, diagnosis and treatment are available for free in the provincial public health care system.

Sample inclusion/exclusion criteria

The population included in the research study was made up of women over 18 who received care in public health care centers of the province of Jujuy between January 1, 2010 and December 31, 2010 and who had the following diagnoses according to the Bethesda cytology classification (15): atypical squamous cells of undetermined significance-cannot exclude high-grade squamous intraepithelial lesion (ASC-H), high-grade squamous intraepithelial lesion (HSIL), and carcinoma. These diagnoses were selected because they are precursor lesions for cervical cancer, for which biopsy and eventual treatment is indicated (16). Women under the age of 18 and women with records of a Pap smear positive for at least HSIL prior to 2010 or who underwent treatment before 2010 were excluded from the study.

Definition of abandonment of the health care process

According to Ramos and Pantelides (13), abandonment of the health care process means that the woman, at some point in the path that begins with the Pap smear, stops going to the health care center of origin and does not go to any other. Using the last health contact recorded, abandonment is defined taking into account the type of medical intervention performed and the time elapsed since it was performed, as detailed below:

1. Abandonment in the screening stage: more than 60 days since the initial Pap smear without receiving/knowing the result;

2. Abandonment in the diagnosis stage: more than 90 days between the delivery of the result and the realization of the biopsy;
3. Abandonment in the treatment stage: more than 90 days between the performance of the biopsy and the realization of the treatment.

Data Collection Techniques

Secondary sources: systematization of available records

Between December 6, 2010 and March 1, 2011, the collection, systematization and analysis of information from the different secondary sources available was carried out, following previous studies (13,17,18).

The province has a screening information system [SITAM 1.0 – Sistema de Información para el Tamizaje] introduced by the National Program. It allows online records to be kept of the procedures done by centers where samples are collected, by laboratories and by treatment facilities, making the follow-up of the women in the different stages of the health care process easier (9). Although this system has been operating in the province since 2009, the information on biopsies and treatments was not comprehensively recorded at the time of the study. Therefore, it was necessary to collect information from other sources: cytology and pathology laboratory records and biopsy and treatment record books of the cervical pathology services. The basic information on the women and their health care process starting with the HSIL Pap diagnosis was transcribed into a unified database taking into account the following variables: the *dates* when each woman contacted the health care system in relation to this health topic; the *procedures* (repetition of Pap smear, colposcopy, biopsy, applied treatment); and the *results* of each procedure carried out.

The variables that were used to match the records and to ensure that the information about the treatment trajectory corresponded to the same woman were the National Identity Document number, ID card number, or the medical record number, last name and first name. In the event of duplications or inconsistencies in the diagnoses and/or personal data, the information was corroborated with the cytology reports available in the laboratory files of the hospital of reference.

Primary sources: interviews with women

Once the unified database was obtained, it was possible to identify women who had no recorded information regarding the performance of diagnostic procedures and treatment. However, this information did not allow us to determine whether the absence of information was due to abandonment of the health care process, to a problem in the records, or to the woman having continued the health care process in another subsector of the health care system (employment-based health insurance or private health insurance). Therefore, it was necessary to interview women who had no record of diagnosis and/or treatment in order to corroborate the information gathered in the records, quantify the abandonment rate and describe more accurately the health care trajectory.

Surveys were carried out in interviewees' homes using a structured questionnaire. The sociodemographic and economic variables included were:

- age in years;
- highest educational level reached: incomplete higher education/complete secondary education, incomplete secondary education/complete primary education, incomplete primary education/ never attended school;
- family status: in a partnership with children, in a partnership without children, single with children, single without children;
- head of household: yes/no;
- occupational status: employed, unemployed, housewife (dedicated to the administration of the household and the care of dependent persons), inactive (student, retired, pensioner, permanently disabled, excluding housework);
- housing status: a) inadequate (houses with at least one of the following characteristics: lack of running water inside the house, the presence of a latrine, dirt floor, or overcrowding – more than three people per room, excluding the bathroom and kitchen) (19) and b) adequate (houses that did not show any of the aforementioned conditions).

The variables included to measure the use of the health care system were: type of health coverage (public, private/employment-based health insurance), and frequency of visits to the gynecologist (every 3/6/12 months, during pregnancies, no established frequency).

The reconstruction of the health care process starting with the Pap smear was carried out through open questions that inquired into the health institutions the woman attended, the methods recommended by the professionals, the methods effectively carried out, and their results.

In order to analyze the quality of the delivery of the Pap smear result, women were asked if they knew the result, the time that had elapsed between the performance of the Pap smear and their reception of the result, and how it was delivered (during a consultation, over the telephone, or during a home visit). Additionally, the following questions were asked to the women who knew the result (n = 71): Did anyone explain to you the meaning of the result? (yes/no); Did anyone explain to you the steps you should follow next? (yes/no); and Did the doctor ask you if you had any questions or doubts? (yes/no). Affirmative answers to these questions were considered indicators of good quality in the delivery of the results.

Women who had abandoned the health care process were asked to identify the main reason they had done so. The reasons were recategorized according to the guidelines used in previous studies (20-22):

1. Reasons related to the organization and operation of the health care system.
    1.1. Reasons related to the organization of services (delays in the delivery of results, difficulties in obtaining an appointment, suspensions of health care services, and long wait times for appointments).
    1.2. Reasons related to the health care process (communication issues in the doctor-patient relationship and bad experiences with the care received).
2. Subjective reasons (fear, fatalism, denial, not considering a follow-up appointment necessary).
3. Personal/family reasons (relationship problems, separations, death of a child).
4. Reasons related to work (unable to miss work).
5. Reasons related to the household workload (care of children or another relative).
6. Reasons related to transportation (lack of money to pay for the trip and distance).

The surveys were carried out by two local interviewers who had been previously trained. Once the survey was over, the women participating were given information about cervical cancer prevention and a referral letter with information about the health institutions and professionals they could contact to continue with the health care process. The referral network was previously agreed upon with the local health care providers to ensure women could be reconnected to the health care services if they had abandoned the care process.

All the women interviewed signed an informed consent form and the project was approved by the Provincial Bioethics Committee of the Ministry of Health of the province of Jujuy. In all cases, the confidentiality of the information and identity of the interviewed women have been respected.

Data analysis

Data was processed and analyzed using the statistical software STATA 10.0. A univariate and bivariate analysis was performed, creating frequency tables and calculating percentages for each variable of the study. The Chi-squared test for independence was used in order to assess the relationship between the independent variables (the sociodemographic and economic variables and those related to the quality in the delivery of the Pap result) and the dependent variable (abandonment of the treatment process). The level of statistical significance established was 0.05.

RESULTS

Magnitude of the abandonment

Between January 1, 2010 and December 31, 2010, a total of 21,304 Pap smears were carried out in the public care health system of the province
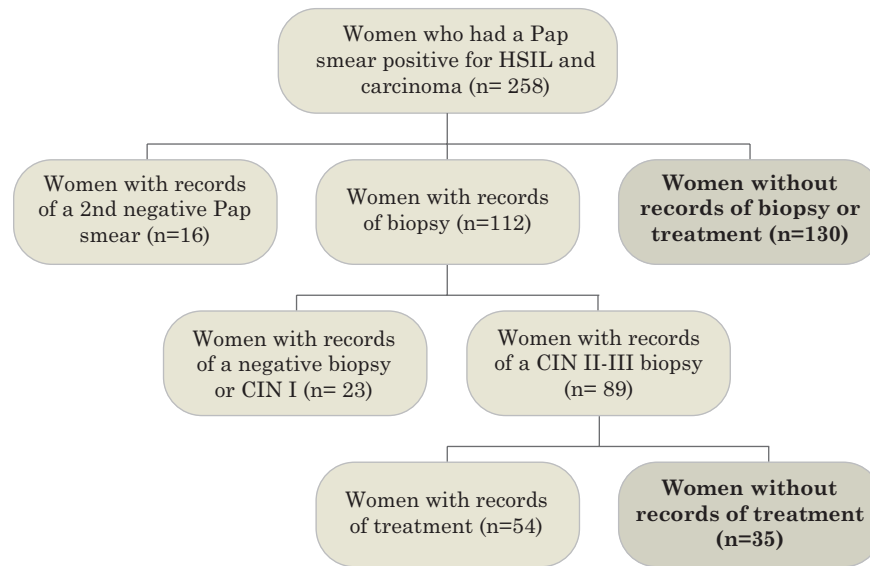
Figure 1. Women with a Papanicolaou test positive for high-grade squamous intraepithelial lesion (HSIL) and carcinoma who received health care in the public health care system of the province of Jujuy, Argentina, 2010.

Source: Own elaboration based on data available in the screening information system SITAM [*Sistema de Información para el Tamizaje*], the databases of the Provincial Cervical and Breast Cancer Prevention and Control Program, records from the pathology laboratory and from the gynecology service of the hospital of reference.

HSIL: High-grade squamous intraepithelial lesion.

of Jujuy. Of these, 297 were positive for HSIL and carcinoma, and they corresponded to 287 women (10 women recorded two Pap smears in the reference period). Twenty-nine women were excluded because they had received treatment in previous years (hysterectomy, cervical conization, or LEEP), so that a total of 258 women were included in this research study.

According to the secondary sources, 93 women (36%) with HSIL and carcinoma diagnoses had complete records of biopsies and/or treatment, and 165 (64%) did not have records of that information: there were no records of biopsies or treatments for 130 women, and for the additional 35 women there were records of biopsies (CIN II-III) but not of treatment (Figure 1).

Of the 165 women eligible to be interviewed, 82 were contacted. It was additionally discovered that three women had died and one woman had had a hysterectomy in 2008. It was not possible to contact 79 women because their home addresses were incomplete, were erroneous or did not exist.

All the women contacted agreed to participate in the research study. In all, the study collected information about 179 of the 258 women diagnosed with HSIL and carcinoma during 2010: 97 women with follow-up and treatment records (including the women who died) and 82 women who were contacted.

Among the 82 women interviewed, 51.2% (n = 42) abandoned the health care process. The remaining 48.8% (n = 40) – which according to the secondary sources did not have records of biopsy and/or treatment – continued with the health care process. Most of these women continued the process in the public health care system, but this information was not recorded at the time of the study's systematization, demonstrating a delay in the processing of records. Only eight women stated having continued their treatment with a private health care provider.

Of all the women regarding whom this study collected information (n = 179), 23.5% (n = 42) abandoned the health care process.

Table 1. Percentage distribution of abandonment of the health care process of women with high-grade squamous intraepithelial lesions (HSIL) and carcinoma, according to sociodemographic and economic characteristics, use of the health system and region of residence. Jujuy, Argentina, 2010.

Characteristics	Women contacted		Abandonment of the care process			
	Total	%	Yes	%	No	%
Total	82	100.0	42	100.0	40	100.0
Age						
18-34	27	32.9	13	31.0	14	35.0
35-55	37	45.1	19	45.2	18	45.0
55 or older	18	22.0	10	23.8	8	20.0
Educational level						
Incomplete primary education/ never attended school	26	31.7	15	35.7	11	27.5
Complete primary/incomplete secondary education	36	43.9	19	45.2	17	42.5
Complete secondary/incomplete higher education	20	24.4	8	19.0	12	30.0
Family Status						
In a partnership with children	43	52.4	21	50.0	22	55.0
In a partnership without children	8	9.8	6	14.2	2	5.0
Single with children	25	30.5	13	31.0	12	30.0
Single without children	6	7.3	2	4.8	4	10.0
Occupation						
Employed	43	52.4	23	54.8	20	50.0
Housewife	23	28.0	11	26.2	12	30.0
Inactive	16	19.5	8	19.0	8	20.0
Housing status						
Adequate	43	52.4	25	59.5	18	45.0
Inadequate	39	47.6	17	40.5	22	55.0
Health insurance						
Employment-based insurance	19	23.2	8	19.0	11	27.5
Public health insurance	63	76.8	34	81.0	29	72.5
Frequency of visits to the gynecologist						
Every 3/6/12 months	24	29.3	12	28.6	12	30.0
Only during pregnancy	10	12.2	3	7.1	7	17.5
No established frequency	48	58.5	27	64.3	21	52.5
Place of residence						
Centro	37	45.1	19	45,2	18	45,0
Ramal	9	11.0	3	7,1	6	15,0
Valles	18	21.9	9	21,4	9	22,5
Quebrada and Puna	18	21.9	11	26,2	7	17,5

Source: Own elaboration.

Note: The *p*-value was not significant for any of the characteristics related to the abandonment of the health care process.

If the percentage of abandonment is estimated considering the 79 women who could not be contacted, there are at least three possible scenarios. If we assume that the 79 women who could not be contacted continued the treatment, the percentage of abandonment would be 16%. If the 79 women who were not contacted had behaviors similar to the women who were contacted (51.2% of abandonment vs. 48.8% of non-abandonment), the overall percentage of abandonment could be estimated at 32%. If all women who were not contacted abandoned the health care process, the percentage of abandonment would rise to 47%.

Characteristics of the women interviewed

Table 1 shows the characteristics of the women interviewed (n=82). Although there are no significant statistical differences between both groups (women who abandoned vs. women who did not abandon), among the women who abandoned the health care process there is a greater percentage of women aged between 35 and 55 (45.2%); with low (35.7%) and medium (45.2%) educational levels; employed (54.8%); with public health coverage (81.0%); and that do not report an established frequency for gynecological visits (64.3%).

Time of abandonment and reasons for abandoning the health care process

In the study, 26.2% of the women abandoned the health care process in the screening stage, 57.1% abandoned in the diagnosis stage, and 16.7% confirmed the presence of a precancerous lesion through a biopsy (CIN II-III) but did not undergo any type of treatment (Table 2).

When we explored the reasons for abandoning the care process (Table 3), 40.5% of the women mentioned reasons related to the organization and functioning of the health care system. In that group, 28.6% mentioned motives related to the organization of the health care services: delays in obtaining the results, problems in making an appoint or long wait times in order to be seen; and 11.9% mentioned reasons related to the health

care process (problems in the communication of the results or bad health care experiences).

In the study, 30.9% of the women who abandoned the health care process reported subjective reasons: fear, denial regarding the disease, or not considering it necessary to continue with the health care process. Other motives mentioned as main reasons for abandoning the care process were: family (7.1%), work (4.8%), the household workload and taking care of the children (4.8%), and transportation issues (4.8%).

Table 2. Percentage distribution according to the stage at which women with high-grade squamous intraepithelial lesions (HSIL) and carcinoma abandoned the health care process. Jujuy, Argentina, 2010.

Stage at which abandonment of the care process occurs	Women with HSIL and carcinoma	
	n	%
Screening	11	26.2
Diagnosis	24	57.1
Treatment	7	16.7
Total	42	100.0

Source: Own elaboration.

HSIL = High-grade squamous intraepithelial lesion

Table 3. Percentage distribution of the reasons for abandoning the health care process mentioned by women with high-grade squamous intraepithelial lesion (HSIL) and carcinoma. Jujuy, Argentina, 2010.

Reasons for abandoning	Women with HSIL and carcinoma	
	n	%
Related to the health care system		
Organization of the services	12	28.6
Health care process	5	11.9
Subjective	13	30.9
Personal/family	3	7.1
Work	2	4.8
Household workload	2	4.8
Transportation	2	4.8
No reason given	3	7.1
Total	42	100.0

Source: Own elaboration.

HSIL = High-grade squamous intraepithelial lesion

After the interviewer's visit, 55% of the women who had abandoned the health care process resumed the process between 10 and 30 days after the interview.

Communication of the results

Although most of the variables related to the quality in the delivery of the results showed no statistically significant differences between the groups, the women who abandoned the health care process reported indicators of good quality to a lesser extent than women who did not

abandon the process. In this way, 42.1% of the women who abandoned the process and 57.9% of those who did not mentioned that a professional of the health system called or visited her at home to deliver the result or to make an appointment in order to do so (Table 4).

In analyzing the quality of the delivery of the results, the women who did not know the results were excluded (n = 11). Among the women who did know the result (n = 71), 38.6% of those who abandoned the health care process and 61.4% of those who did not stated that the doctor had explained to them the meaning of the result. Similarly, 33.3% of those who abandoned and 66.7% of

Table 4. Percentage distribution of abandonment of the health care process according to quality indicators perceived by women with high-grade squamous intraepithelial lesions (HSIL) and carcinoma. Jujuy, Argentina, 2010.

Perceived quality indicators	Women contacted		Abandonment of the care process			
	Total	%	Yes	%	No	%
Did a professional visit/call you to deliver the results?						
Yes	38	100.0	16	42.1	22	57.9
No	44	100.0	26	59.0	18	41.0
Total	82	100.0	42	51.2	40	48.8
Time it took to obtain the results*						
1 to 4 weeks	44	100.0	21	47.7	23	52.3
5 weeks or more	27	100.0	10	37.0	17	63.0
Total	71	100.0	31	43.7	40	56.3
Did anyone explain to you the meaning of the result?*						
Yes	57	100.0	22	38.6	35	61.4
No	14	100.0	9	64.3	5	35.7
Total	71	100.0	31	43.7	40	56.3
Did anyone explain to you the steps you should follow next?*						
Yes	38	100.0	11	33.3	22	66.7
No	38	100.0	20	52.6	8	47.4
Total	70	100.0	31	43.7	40	56.3
Did the doctor ask you if you had any questions or doubts?**						
Yes	21	100.0	4	19.0	17	81.0
No	40	100.0	19	47.5	21	52.5
Total	61	100.0	23	37.7	38	62.3

Source: Own elaboration.

Note: The *p*-value only was significant for the perceived quality indicator referring to whether the doctor had asked the woman if she had any questions or doubts (*p*=0.029).
*The 11 women who did not know the result of the Pap were excluded.
**The 11 women who did not know the result of the Pap and 10 lost cases were excluded.

those who did not stated that the doctor adequately explained to them the following steps to take. The question regarding whether the doctor had asked them if they had any doubts about the result or the steps to follow was answered by 61 women who knew the result. Of these, 19.0% of the women who abandoned and 81.0% of the women who did not answered affirmatively ($p = 0.029$).

DISCUSSION

To our knowledge, this is the first research study that analyzes, for a given year, the extent of abandonment and the reasons that lead women who received health care in the public health care system of an Argentine province with high mortality rates due to cervical cancer to abandon follow-up and treatment after a Pap smear result positive for HSIL and carcinoma.

In our research study, the percentage of abandonment was 23%, with a possible fluctuation between 16% and 47% depending on how the behavior of the women who were not interviewed is considered. Research studies from the US and Europe show abandonment rates of between 10% and 45% (18,23-25). In Latin American countries, where cervical cancer prevention programs have not achieved the expected results (26), the percentages are higher: between 20% and 75% (13,17,22,27-30). Although comparisons should be undertaken with caution – considering the differences in the health care systems, the populations included in the studies and the definitions of abandonment – the estimated percentage of abandonment for the province of Jujuy is similar to the percentages reported in studies from Mexico, Colombia and Brazil: 20%, 27% and 29% respectively (22,28,29).

Given the impact that adequate follow-up and treatment have in the reduction of mortality caused by cervical cancer (10), lowering the percentage of abandonment represents an important challenge for all cervical cancer prevention programs in Latin America. Most of these programs have prioritized actions aimed at achieving wide screening coverage; however they do not demonstrate similar efforts towards achieving adequate diagnosis and treatment of women with precancerous lesions (31). In the present context of the incorporation of new screening technologies (32), whatever the screening test used it is necessary for health systems to be articulated and for adequate diagnosis and treatment of women with precancerous lesions to be guaranteed.

In our study, abandonment mostly took place in the diagnosis stage, that is to say, after obtaining the result and before undergoing a biopsy. These results are consistent with other research studies (22,28) and can be considered indicators of flaws in the transferal of information and responsibilities between screening services and diagnosis and treatment services, also seen in other studies (20,27). When a woman receives a referral to undergo a biopsy, her health care trajectory takes her away from the professional who did her screening; this professional in many cases does not know the final result of the process (12). The identification of professionals responsible for the follow-up of women with HSIL and carcinoma in each region, the implementation of systems of notifications/alarms for these cases and the reformulation of the referral and counter-referral system are possible strategies to improve the trajectory of women among the different institutions involved and to avoid abandonment in key moments of the process. Furthermore, these strategies require a system of information that allows for monitoring the process. The absence of systematic records about follow-up and treatment is a problem that has been reported in Latin America (27,31) as well as in Argentina (12,33). The fact that at the beginning of the project the health care system did not have information regarding the diagnosis and treatment of 64% of the women with Pap smears positive for HSIL and carcinoma revealed flaws in the information record system that was being implemented up until that point. The results of the research study were discussed in meetings with the authorities and with local health care providers. In those meetings, obstacles to recording the information of the patients were identified and strategies for improving data entry and the use of the information supplied by the SIS, as an important measure for reducing abandonment, were discussed.

Regarding the reasons for abandoning the health care process, women first mentioned aspects related to the organization of the health

services. The institutional obstacles that cause women to abandon the process are similar to those reported by research studies in Latin America (12,13,22,27,28). The results regarding these obstacles were analyzed in conjunction with the health authorities of the province with the objective of reformulating some organizational aspects of the screening-follow-up-treatment process. There were several modifications, but the most significant ones were the increase in the availability of biopsy appointments for women with HSIL and carcinoma, the reorganization of patient referral networks in different regions of the province, and the implementation of the Navigator project starting in July 2011, which was promoted by the National Ministry of Health. This project provides human resources whose main role is to support women in need of diagnosis and treatment to reduce the social and institutional barriers to health care access.

Secondly, women mentioned subjective reasons for abandoning the process. These results coincide with the vast evidence stating that the perception and knowledge women have regarding cervical cancer, prevention methods and treatments are factors that condition practices in relation to the disease (13,22,28,34-36), either causing the abandonment of the follow-up and treatment process (22,28,34) or acting as a barrier to getting a Pap smear (35,36). These results reflect the importance of considering the symbolic aspects of the disease when deciding upon public health strategies to reduce abandonment rates. The reasons women do or do not use the services will be subject to their perceptions about their health, their ailments and the existence or nonexistence of a solution to those problems (37). Eliminating these subjective barriers to care requires comprehensive strategies that include counseling services in which the needs of women are heard and incorporated into the solution of the problem.

The results show that a smaller proportion of women who abandoned the health care process mentioned indicators of good quality in the delivery of the results than women who did not abandon the process. Although there were no statistically significant differences between the groups (perhaps because of the size of the sample used), these results coincide with research studies that show the influence of inadequate communication between health professionals and women in women's abandonment of the follow-up and treatment process (30,38,42). Therefore, it is possible to consider that the delivery of the results is a key element for analyzing such abandonment. Several research studies have demonstrated that difficulties in the relationship between professionals and women lead, in some cases, to an inadequate interpretation of the meaning of an abnormal Pap smear (39-42) or to situations that cause anxiety or stress that act as barriers to compliance with treatment (40). Although the women who abandoned treatment reported lower quality in the delivery of the results, only four of them mentioned problems in the delivery of the results as a reason for abandoning the process. While it is necessary to explore this matter further in future research studies, a possible explanation could be the naturalization of the characteristics of the health care process – an asymmetric doctor-patient relationship, the undervaluing of knowledge other than biomedical knowledge (43) – that often place women in a role of passive patients and that can act as barriers to care, even when they are not specified as such. Research studies based in the observation of medical consultations show that when a space for the emotional dimension and attentive listening is opened, a closer communication between users and professionals is produced and better results in the health care process are achieved (44,45). The creation of specific spaces for delivering results, designed according to the needs of women, can help reduce the number of situations that generate stress or anxiety. The creation of these spaces requires a specific training process regarding adequate capacities and techniques for delivering results.

There are some limitations in our research study that must be taken into account. It was not possible to collect information for 30.6% (n = 79) of the total number of women diagnosed with HSIL and carcinoma (n = 258). This fact might produce an underestimation of the abandonment rate, which is why a possible fluctuation in the abandonment (between 16% and 47%) was calculated in the results according to how the behavior of the women who were not contacted is estimated. Another limitation of this research study is that the analysis of the differences between the group of women who abandoned the process and the group of women who did not abandon

the process did not include the 93 women with records of follow-up and treatment. This methodological decision was made based on the logistical difficulty entailed in searching for women living in different areas and localities of the province. As the resources available for the research study were limited, priority was given to seeking out women without records of follow-up and treatment, assuming that they were the most vulnerable and would therefore most benefit from the contact with the interviewer. This analysis also did not include the 79 women without records that could not be contacted due to errors in the contact information. If the existence of information records is considered to be an indicator of better quality in the health care process (46), it is probable that this analysis is underestimating the differences in the quality of the delivery of results found between women who abandoned the process and those who did not. If this hypothesis is true, it would further reinforce the influence of inadequate communication between health professionals and women in the abandonment of the follow-up and treatment process detected by our research study.

It is necessary to develop new research studies to investigate this matter in greater depth.

CONCLUSION

The results of this research study have put into evidence a problem which was invisible to the public health agenda of the province and therefore have permitted the introduction of modifications to the services involved in cervical cancer prevention. Although the obstacles to health care have not been completely eliminated, this has been a necessary first step towards reducing the abandonment rates and the barriers that women face to accessing health care. The fact that more than half of the women contacted who abandoned the follow-up and treatment process returned to the health care system immediately after being interviewed indicates that the measures that are being implemented in the province can provide good results in the short or medium term.

FINAL NOTES

a. The Papanicolaou test (or conventional cytology) identifies cervical lesions in the pre-clinical stage (precancerous lesions). If the lesion is detected, the slow progression of the disease allows for treatment to be carried out before it turns into cancer. According to the specialized literature, an organized screening program is defined as an integrated system in which women are invited to participate, undergo a screening test, obtain the results (in due time and manner), are referred for treatment, if necessary, and return to repeat the screening according to the recommendation. The final objective of the prevention program is to reduce the incidence and mortality caused by cervical cancer. In order to achieve this, a program must comply with three basic conditions: a) wide coverage of the target population, b) screenings carried out with tests of good quality, c) adequate treatment and follow-up of women with precancerous lesions and cancer.

b. The prevention through screening strategies is different from the diagnosis; they are two stages of the same process. Screening is oriented towards subjects considered "healthy" in order to identify a relatively small number of individuals among them who should undergo complementary detection tests to determine the existence of a premalignant lesion or cancer.

c. The loop electrosurgical excision procedure (LEEP) is a relatively simple procedure for the treatment of precancerous lesions, in which a thin conductive wire loop is used to remove the abnormal area of the cervix.

d. The methodological design used in this research study, as well as its results, are found within Melisa Paolino's dissertation project as candidate for PhD in Social Sciences (Universidad de Buenos Aires), directed by Dr. Silvina Arrossi. An adaptation of this protocol is also being used in a project which is currently taking place in the Municipality of Florencio Varela, Buenos Aires (Project PICT-2008-1545), financed by the National Agency for Scientific and Technological Promotion, Fund for Scientific and Technological Research.

e. Since 2011, the National Cancer Institute and the National Program for the Prevention of Cervical Cancer, along with the Ministry of Health of Jujuy have been implementing a demonstration project that incorporates the Human Papillomavirus (HPV) test as a primary screening test in the entire province (14).

CONFLICTS OF INTEREST

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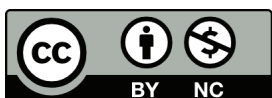
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