ORIGINAL ARTICLES

Adherence to recommended follow-up care after high-grade cytology in El Salvador

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ABSTRACT

Objective: To quantify adherence to recommended follow-up care among women in the Paracentral region of El Salvador who were diagnosed by cytology with high-grade squamous intraepithelial lesions (HSIL) of the cervix.

Materials and methods: A retrospective chart review was conducted to determine follow-up in the first year after cytological diagnosis of high-grade cervical dysplasia (HSIL). A small sample of these women were also interviewed to determine barriers to care.

Results: Patient charts were available for 99 study-eligible patients with HSIL. Only 44% (44/99) of women completed recommended follow-up. Among the 55 women who did not complete follow-up (56% of 99 reviewed), loss to follow-up occurred when women did not schedule a colposcopy appointment (61.8%), did not receive their cytology results (20%), did not return to the clinic to receive their biopsy results, (9.1%), or did not attend their scheduled colposcopy (1.8%). No other factors had a significant effect on adherence to recommended follow-up. An additional 7.3% did not complete their treatment within the one-year time frame designated by the study to represent completion of follow-up. Failure to follow-up among the 13 non-compliant women interviewed was due to lack of money (38%), appropriate referral (28%), and fear (15%).

Conclusions: The likelihood of non-adherence increased with longer wait times for follow-up appointments. The data supports the need for systemic interventions to decrease wait time for colposcopy. Changes in both systems and infrastructure have been initiated in El Salvador in order to establish more reliable methods for efficient follow-up care. Further investigation of barriers to care at every point in the process of cervical cancer screening and treatment will highlight which steps require modification.

Key Words: Cervical intraepithelial neoplasia, Prevention and control, Follow-up high-grade cytology, Adherence colposcopy, El Salvador

1. INTRODUCTION

Cervical cancer is a leading cause of cancer-related death in many low-resource settings.[1] El Salvador has an estimated annual incidence of 24.8 and a mortality rate of 11.9 per 100,000 women.[2] A cytology-based cervical cancer prevention program was established in El Salvador in 2001,

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yet rates of screening remain low.[3–7] Agurto et al. (2004)[4] posited that the primary barrier to the prevention of cervical cancer in low-resource settings is not the cost of a screening test, but rather the cost and complexity of providing the infrastructure necessary for a comprehensive program. Murillo et al. (2008)[8] showed that even when cytology coverage rates improved, there was no significant decrease in mortality from cervical cancer.

In low-resource settings, barriers both from delivery of health services and those pertaining to women's beliefs about cervical cancer and screening have been recognized. These include inconvenient clinic hours and locations, fear of embarrassment or pain, lack of female health care providers, anxiety about abnormal Pap results and cancer, and poor understanding of screening.[4,9,10] Barriers impact patient selection, sample collection, access to treatment, and other steps in cervical cancer prevention efforts.[11,12] A study consisting of a series of interviews conducted with 30 healthcare professionals across institutions in several regions of Peru found that two major structural barriers to effective screening were the widespread lack of resources and the centralization of cervical cancer treatment and cytology services in the capital, and revealed that women could access screening but not easily obtain treatment.[13]

Historically, El Salvador has had the lowest reported cervical cancer screening coverage (19%) among all Latin American countries,[8] with the Pap smear the most common method of screening. Alternatives to the Pap smear, such as visual inspection with acetic acid (VIA) and HPV-DNA testing, are gaining acceptability in El Salvador; however, cytology remains the most widely used screening method. A study conducted by the Pan American Health Organization (PAHO) in El Salvador in 2002 showed that only 24% (22/90) of women with abnormal Pap smear results received a follow-up colposcopy.[5] Inadequate follow-up of abnormal cytology results means that many women do not obtain the necessary treatment to prevent cervical cancer.

This study aims to identify factors associated with loss to follow-up care in a single low-resource region of El Salvador. The main objectives were to determine adherence to recommended follow-up care among women diagnosed with high-grade squamous epithelial lesions (HSIL) by Pap smear and to contact non-adherent women to explore their understanding of the follow-up process and barriers to care. To date, this is the only study conducted in El Salvador that has calculated rates of adherence and identified factors associated with non-adherence to follow-up care.

2. MATERIALS AND METHODS

The study was reviewed and approved by the Institutional Review Board of Johns Hopkins University and the national ethical review board of El Salvador.

2.1 Participant selection- HSIL diagnosis

The study sample consisted of women in the Paracentral region of El Salvador diagnosed with HSIL in 2009. Study researchers, including two physicians and a medical student, identified potential participants by cross-referencing a national database against records at the sites where women were screened and treated. First, all patients with an HSIL diagnosis in the Salvadoran Ministry of Health (MOH) database were identified. Next, the researchers attempted to locate all corresponding cytology charts maintained by local health units, larger regional health centers, and hospitals in order to verify the HSIL cases.

According to the national database, there were 369 Paracentral women diagnosed with HSIL. Women were included if they were 18 or older and had an HSIL Pap smear in 2009. Exclusion criteria included pregnancy at the time of the Pap smear and a surgical history of hysterectomy. Of the 369 cases reviewed, 148 met the criteria and were available at the time of the study. Following identification in the national database, research assistants visited regional health centers, health units, and hospitals and attempted to locate the matching cytology records. Every attempt was made to verify cases, however, some charts were incomplete and others could not be located.

2.2 Participant selection-adherence to follow-up

Cytology records were then matched with colposcopy and treatment records from five referral sites and evaluated for adherence to follow-up care. Records of 99 of the 148 HSIL cases were located; follow-up was completed by 44/99 women. Women were considered adherent if they fulfilled the following steps: received their Pap results, underwent colposcopy, received their biopsy results, and completed the treatment recommended by MOH guidelines within 12 months of screening.

2.3 Study instruments

A chart review instrument was developed to collect information from clinic and hospital records about completion of follow-up for abnormal Pap smear results. This instrument was also used to collect demographic information including age, marital status, number of children, smoking status, education level, and distance lived from the clinic. Information obtained with the survey instrument was entered into an Excel database.

Health care promoters attempted to locate the 55 women whose treatment records indicated they did not complete follow-up. Among women who were reached and agreed

to participate, medical students conducted interviews that explored: what they perceived as barriers to accessing treatment; whether they received their Pap smear result; whether they understood the Pap smear result; and whether they sought treatment outside the public health system. Following the interview, study personnel provided information on obtaining follow-up care appropriate to the diagnosis if the women did not attend their treatment appointments.

2.4 Statistical analysis

A two sample t-test was used to compare mean age, number of living children, number of births, and time to referral between adherent and non-adherent women. Fisher exact tests were used to compare the proportion with a history of previous abnormal cytology and partnered relationship status. Statistical analyses were performed using STATA.

3. Results

Demographic and screening history data of the 99 women with HSIL is presented in Table 1. Overall, the women had a mean age of 42 years and an average of four children. Twenty-six percent of women had a previous history of abnormal cytology results before the HSIL diagnosis. Less than half of the women (44.4%, 44/99) completed treatment within 12 months, and 51.5% (51/99) did not complete treatment within this time frame. The remaining 4.0% (4/99) completed treatment more than a year after screening.

Table 1. Demographics and screening history based on chart review (n=99)

Subject Demographics	Adherent	Non-Adherent	*p*-value
Mean Age - years	41.6 (16.2)	41.8 (15.6)	.943
Relationship Status (Partnered)	62.5%	66.7%	.823
Mean # living children	3.7 (3.4)	4.2 (2.6)	.415
Mean # of births	4.0 (3.7)	4.7 (3.1)	.393
History of previous abnormal cytology	13.3%	26.3%	.236
Mean time to referral - days	59.1 (29.7)	93.2 (101.6)	.051

Note. Standard deviations are provided in parentheses.

Women were lost to recommended follow-up at various points after the HSIL Pap smear: 61.8% (34/55) did not receive a colposcopy appointment; 20.0% (11/55) did not receive the Pap result; 9.1% (5/55) did not return for the biopsy result and treatment after colposcopy; and 1.8% (1/55) did not attend their colposcopy appointment (see Table 2). Women who did receive treatment obtained their Pap result an average of 59.1 days after screening, while those who did not receive treatment obtained their Pap result an average of 93.2 days after screening (p = .05).

Table 2. Step in cervical cancer screening and precancer treatment process where loss to follow-up occurred (n=55)

	n (%)
Did not schedule colposcopy appointment	34 (61.8)
Did not receive Pap results	11 (20.0)
Did not return for biopsy results after abnormal colposcopy	5 (9.1)
Did not complete treatment within 1 year	4 (7.3)
Did not attend colposcopy appointment	1 (1.8)

Thirty of the 55 women whose charts were missing information or unable to be located were reached and consented to participate in an interview (see Figure 1). Of the 25 who did not participate in interviews, 21/25 (84.0%) were not reachable, 3/25 (12.0%) declined to participate, and one (4.0%) had died. The 30 women who were interviewed had a mean age of 35 years and an average of three children, and one-third (10/30) had a previous history of abnormal cytology.

Seventeen of the 30 women interviewed (56.6%) adhered to treatment recommendations within 12 months and 13 (43.3%) were non-adherent. Of the 13 non-adherent women, seven (53.8%) did not have the recommended colposcopy because they either did not receive a referral (2/7, 28.5%) or they received a referral but did not attend the appointment (5/7, 71.4%). One of the 13 (7.0%) completed her treatment beyond the recommended 12-month post-screening time frame. Five of the 13 (38.4%) attended their colposcopy appointments but did not return for their biopsy results.

A total of five of the 13 non-adherent women (38.4%)-two did not attend their colposcopy appointments and three had colposcopy but did return for their biopsy reports-responded that they did not complete treatment because they could not afford transportation to the hospital. Two of the 13 (15.3%) responded that they were afraid to continue with their follow-up, and 1/13 (7.7%) responded that she did not think completing follow-up was important. The remaining five women (38.4%) did not give a reason for their non-adherence.

4. Discussion

Adherence to recommended follow-up is a significant challenge in successful cervical cancer prevention programs. The

review of charts for women with complete records revealed that less than half the women adhered to follow-up recommendations within 12 months of HSIL diagnosis. Among the women interviewed because their follow-up records were incomplete or missing, more than half had complied with treatment recommendations; of those who were non-adherent, more than one-third cited a lack of money as the reason they could not complete follow-up.

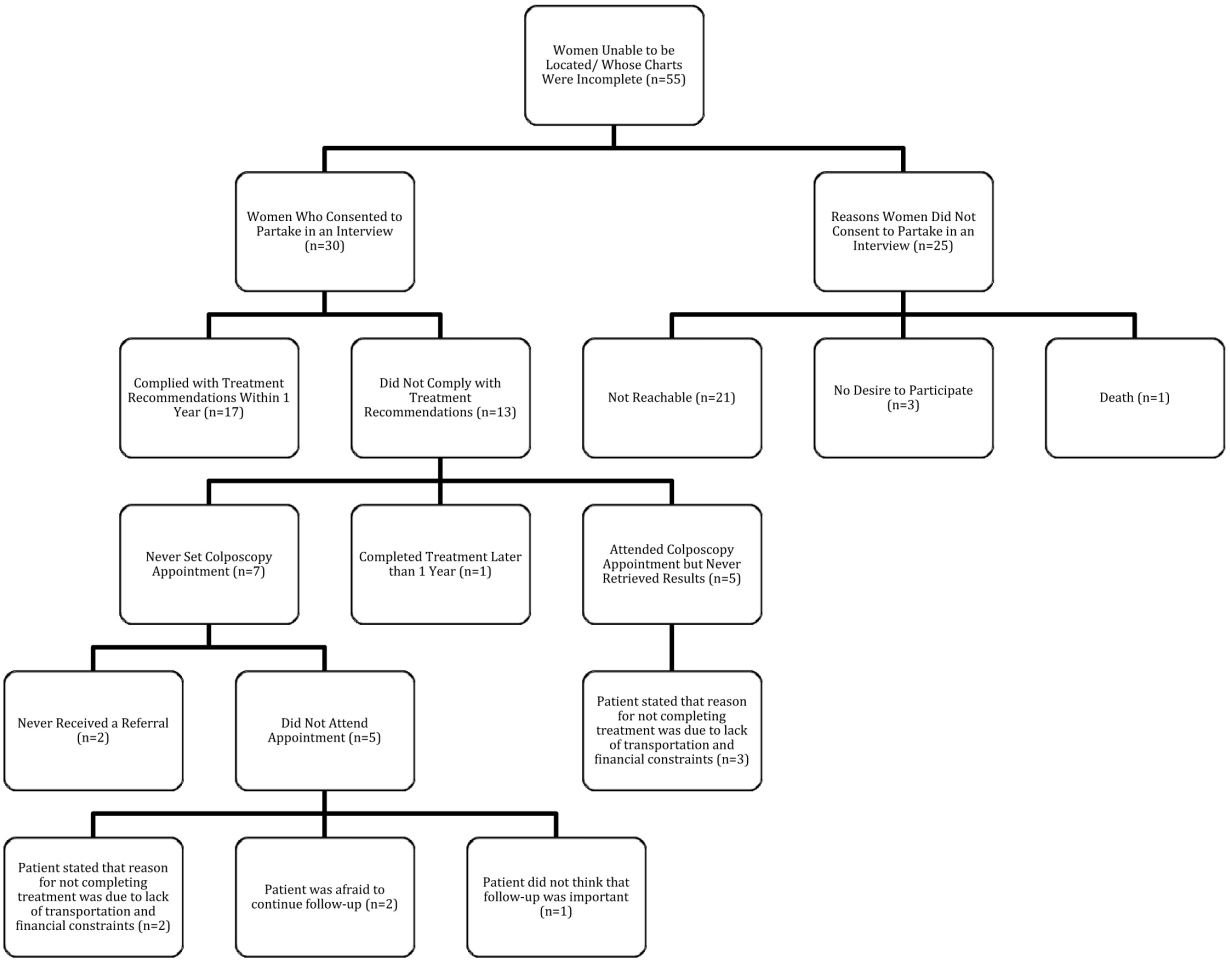

Figure 1. Reasons for lack of follow-up among women who were unable to be located or whose charts were missing

Similar studies done in rural Peru and Jamaica revealed adherence rates of 25% and 51.2%, respectively.[14,15] In Peru, requirement of a co-payment to receive follow-up care was noted as a barrier for most non-adherent women.[14] In El Salvador, the MOH does not charge a co-payment for cytology, colposcopy, or follow-up treatment (cryotherapy, conization, or LEEP). In the Paracentral region of El Salvador at the time of the study, women were charged 20 dollars for biopsy results at one of the regional hospitals. In Jamaica, significant determinants of follow-up care included monthly household income, perceived cost of services, learning about the consequences of not having follow-up care, and receiving explicit directions about the next steps after an abnormal Pap.[15] Women who were given recommendations about timing of follow-up care were nearly six times more likely to be adherent.[15]

In this study, the longer the time between screening and obtaining the results and a subsequent referral appointment for colposcopy, the less likely women were to adhere to treatment, though the difference was on the border of statistical significance. In El Salvador at the time of this study, a woman only obtained her cytology result if she returned to the primary health unit. If the result was abnormal, she was advised to make a separate visit to schedule a colposcopy appointment at the closest hospital. As a result of this study, the MOH modified its referral system so that women learn their cytology results and are provided with the date, time, and location of their colposcopy appointments during the same health unit visit, reducing the number of visits required to complete treatment.

Additional policy changes have been implemented in El Salvador. In September 2010, the MOH announced the launch of a series of health reforms aimed at increasing access to care for the country's most vulnerable citizens. Teams of family healthcare providers and specialists have been placed in communities with limited preventive health services.[16] The national cytology laboratory system has improved its quality control procedures. Still, many barriers to successful Pap smear screening remain: inadequate facilities, shortage of trained professionals, lack of supplies, limited transportation for the transfer of specimens to clinics and pathology laboratories, and excessive wait times for women to receive results, obtain colposcopy, and undergo precancer treatment.

Each of these factors contributes to El Salvador's stagnant cervical cancer incidence and mortality rates despite decades of financial investment in the national screening program.[17] Alternative screening and treatment paradigms that avoid these barriers may be a practical alternative for the future. For example, a study in Honduras comparing adherence rates after screening with either Pap smears or visual inspection with acetic acid (VIA) found that only 38% of women with abnormal Pap results adhered to recommended follow-up versus 84% of women with abnormal VIA results.[18]

A major strength of our study is that it pinpoints the exact step during which the majority of women did not continue their recommended follow-up. Since 62% of women were lost between receiving their abnormal Pap result and scheduling a follow-up colposcopy, the MOH had sufficient evidence to implement a direct referral system between the primary health units where women obtain their results and the nearest hospital where colposcopy services are provided. This intervention is expected to improve adherence to treatment by reducing the time between obtaining a referral for colposcopy and actually receiving the colposcopy. Additionally, during the course of this study all women who had not completed their treatment were identified and provided with a new colposcopy appointment in collaboration with the MOH.

A major limitation of this study is that due to inconsistent and often complex local record keeping, our study sample is small, thus limiting the study's generalizability. Also, only 30 women were interviewed regarding their reasons for not completing proper follow-up care, limiting the ability of the study to fully investigate the reasons for poor adherence to follow-up care in this population.

Changes in both systems and infrastructure have been initiated in El Salvador in order to establish more reliable methods for efficient follow-up care. Cervical cancer screening and treatment programs, particularly in low-resource countries, will benefit from research evaluating the impact of these changes. Further investigation of barriers to care at every point in the process of cervical cancer screening and treatment will highlight which steps require modification. Subsequent changes should increase screening coverage and treatment adherence, eventually decreasing the burden of cervical cancer in low-resource settings. There remains more work to be done to ensure that women at high risk for cervical cancer receive proper treatment.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare no conflicts of interest.

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