

## CLINICAL REVIEW

# Adherence to Care Plan in Women With Abnormal Papanicolaou Smears: A Review of Barriers and Interventions

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**Background:** Cancer of the cervix is preventable. According to the Surveillance, Epidemiology, and End Results (SEER) Program, invasive cervical cancer incidence is 9.0 and cancer mortality rate is 2.8 per 100,000 persons. Effective prevention includes appropriate use of Papanicolaou smears and adherence to a care plan by the patient. This review will examine the extent of nonadherence, negative outcomes, barriers, and interventions for improved adherence to care.

**Methods:** Computer searches in MEDLINE for English language articles were conducted from 1968 to 1999 using the key words "colposcopy," "abnormal Papanicolaou smear," "patient compliance," "adherence to care," and "follow-up."

**Results:** Although there is 10% to 40% nonadherence in the studies reviewed, the definition of nonadherence is not standard. Considerable morbidity from cervical cancer was described among nonadherent women. The most common barriers to follow-up were lack of understanding of the purpose of colposcopy, fear of cancer, forgetting appointments, and lack of time, money, or childcare. Emotional consequences of abnormal Papanicolaou smears had considerable impact on follow-up visits. Focused intervention strategies targeted to the study population were most effective in improving adherence.

**Conclusions:** Nonadherence results from the interplay of emotional, logistic, cultural, or socioeconomic factors. Among the most effective strategies to improve adherence are personalized reminders to patients by their primary physicians and case management dictated by the size, structure, and style of the practice. (J Am Board Fam Pract 2001;14:123–30.)

Cervical cancer was once a common cause of death for American women. It is now the ninth most deadly cancer. Despite widespread screening in the United States, in the year 2000 about 12,800 new cases of invasive cervical carcinoma will be diagnosed, and about 4,600 deaths will result from this disease.<sup>1</sup> According to the Surveillance, Epidemiology, and End Results (SEER) Program, the incidence of invasive cervical cancer is 9.0 percent and cancer mortality rate is 2.8 per 100,000 persons.<sup>2</sup>

The Papanicolaou smear was introduced by Papanicolaou in the 1930s and endorsed by the American Cancer Society in 1945 as an important cancer-screening tool. Increased use of the Papanicolaou

smear has significantly reduced the number of deaths related to cervical cancer since the 1950s. The Papanicolaou smear itself is one component of a larger cervical cancer prevention system, which includes education, examinations, laboratory testing, and clinical procedures. This system is far from perfect, as shown by continuing morbidity and mortality from a preventable cancer.<sup>3–6</sup>

Cervical cancer-screening and treatment systems can be deficient in several ways.<sup>7</sup> Cancer screening is underutilized by ethnic minorities, persons living in rural areas, the poor, the uninsured, and the elderly.<sup>8</sup> Failures can result from errors in obtaining appropriate samples, inaccuracy of the test itself, incorrect interpretation of smears, and inaccurate reporting of results.<sup>3,4</sup> Failures can also occur after the cervical smear results are reported, as shown in Table 1. In addition, aspects of patients' biologic, psychologic, or social spheres can hinder or enhance their ability to adhere to the care plan communicated by their provider.

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**Table 1. Possible Obstacles in Effective Screening of Cervical Cancer.**

Laboratory	Provider	Patient
Poor sampling technique	Papanicolaou results not received	Fear of colposcopy
Incorrect reading	Papanicolaou results not interpreted correctly	Fear of cancer
Incorrect reporting	Unable to contact patient or ineffective communication of result	Health beliefs (disbelief in the importance of early screening)
	Recommend incorrect follow-up	Lack of money, transportation, or childcare

This review will examine the extent of nonadherence to care plan, the negative outcomes that result, and the studies on barriers to and interventions for improved adherence to care.<sup>5</sup>

## Methods

Computer searches were conducted in MEDLINE for English language articles from 1968 to 1999. Key words used in the search were "colposcopy," "abnormal Papanicolaou smear," "patient compliance," "adherence to care," and "follow-up." A careful review of bibliographic references in the selected articles resulted in pertinent references to be reviewed. Attention was directed at works examining the morbidity and mortality associated with nonadherence, as well as behavioral factors, psychologic consequences, ethical considerations, and barriers to follow-up. Studies using intervention strategies were also reviewed.

## Definition of Adherence

Although often used to describe an important aspect of patient behavior, the terms "nonadherence," "noncompliance," and "default" are infrequently defined by study authors. For the purposes of this review, the above terms will be considered roughly synonymous and will be collectively referred to as "nonadherence." For the purposes of many studies on Papanicolaou smear follow-up, nonadherent patients are operationally defined as patients with abnormal findings on Papanicolaou smears who do not have documented evaluations or treatments within a specified amount of time.

## Results

### Rates of Nonadherence

Little consistency exists among studies designed to determine the rate of nonadherence with follow-up for abnormal findings on Papanicolaou smears. Comparison between studies is limited by differences in researchers' definitions of nonadherence

and by differences in study populations and locations. Many studies simply document the number of patients who lack follow-up in accordance with established treatment guidelines. Such studies were unable to distinguish important subgroups of nonadherent patients: (1) patients who were aware of the Papanicolaou smear results and care plan, but chose not to adhere; (2) patients who were interested in adhering to the care plan, but were unable, because of financial or other practical barriers; and (3) patients who followed their provider's recommendation, but these recommendations deviated from the standard follow-up guidelines. Overall rates of nonadherence in surveys or control populations range from less than 10% to more than 40%.<sup>9-23</sup>

A large-scale Australian study followed patients with mildly abnormal or inconclusive findings on Papanicolaou smears. Overall, 64% of these patients had repeat smears within 3 months of the recommended time, and 85% were eventually screened again. This finding suggests a major lack of adherence for even the least invasive option for abnormal Papanicolaou smear follow-up.<sup>24</sup> A survey of patients with normal and abnormal Papanicolaou smears in Australia indicated that among those patients who confirmed being correctly informed of abnormal results and who recalled recommendations for follow-up testing, 15% to 20% had not followed the recommendations. A large proportion of patients who did not receive proper follow-up care, however, were either not informed or were not aware of the correct result or its importance.<sup>9</sup>

Retrospective analysis of more than 1,000 patients with abnormal findings on Papanicolaou smears in Nottingham, UK, found 41% lacking adequate follow-up.<sup>25</sup> A broad survey of organized cervical cancer-screening programs in Italy indicated an overall adherence to colposcopy of 81%, with a large variation between individual programs

(<60% to 95%).<sup>26</sup> Moreover, of the 434 patients without adequate follow-up, only 7% were properly informed of the Papanicolaou smear result and need for subsequent care. Most of the remaining cases of nonadherence were attributed to lack of recommendation of correct follow-up or lack of communication of results and recommendations. Taken together, these studies suggest that nonadherence is a global problem, that both patients and providers share responsibility for the problem, and that ineffective communication of results and recommendations by providers is an important factor in nonadherence.

### ***Morbidity and Mortality as a Consequence of Nonadherence***

Nonadherence has been implicated as a contributing factor in adverse outcomes in retrospective analyses of advanced cervical disease.<sup>26,27</sup> Kinlen and Spriggs<sup>28</sup> prospectively studied patients with abnormal Papanicolaou smears who lacked adequate follow-up for 2 or more years. Of 60 cases of delay in follow-up, 10 patients had invasive carcinoma, and 23 others had serious lesions on later biopsy. Of the cases of cervical carcinoma, 5 patients had died, of whom 4 had missed appointments, refused appointments, or refused examinations, and 1 had not received follow-up care appropriately.

In a retrospective study, 63 cases of invasive cervical cancer diagnosed in a Portland, Ore, health maintenance organization population were reviewed. There were 19 cases (30%) in which invasive cancer developed in patients who had inadequate follow-up of previous abnormal Papanicolaou smear findings.<sup>23</sup> A retrospective review of 245 Canadian patients with invasive cervical carcinoma found 31 patients who had a history of abnormal Papanicolaou smear findings and inadequate follow-up. Neither the Oregon nor the Canadian studies attempted to distinguish whether cases of inadequate follow-up were due to a failure by health care providers to communicate results and recommend follow-up or due to a failure of duly informed patients to adhere to recommended treatment.

A retrospective review of 100 cases of invasive cervical cancer found 13 cases in which reviews of medical records suggested inadequate follow-up of abnormal Papanicolaou smear results.<sup>27</sup> The authors concluded that rigorous implementation of screening policies could have improved the out-

come in a substantial proportion of the cases. These studies emphasize the importance of addressing nonadherence and improving patient follow-up for abnormal Papanicolaou smear findings.

### ***Barriers to Follow-Up of Abnormal Papanicolaou Smears***

A number of studies have attempted to determine what factors are associated with differences in adherence within populations.<sup>9,-11,14,17-22,25-31</sup> As with other studies regarding adherence behavior, these studies differ in the definitions of adherence, the number of patients, the type of study locations, and the type of patients. In addition, nearly all studies examine adherence behavior in small populations in a single geographic area and therefore might not have results that can be generalized. Other bias includes a difference in research focus, from primarily on emotional aspects of cancer screening to determining protocols to reduce the incidence of invasive carcinoma. These differences are likely responsible in part for the varying conclusions drawn in these studies. For example, many researchers found associations of older age and higher education level with greater adherence or no association, but Paskett et al<sup>32</sup> determined that older age and higher level of education were associated with a significant lack of adherence.<sup>11,12,14,17,19,20</sup>

Among studies with larger subject populations (400 or more), a number of trends become evident: younger age, minority ethnicity, lower education level, and lower grade abnormalities on Papanicolaou smears tend to be associated with decreased adherence, whereas marital status, insurance type, and patient income generally did not show associations with adherence behavior.<sup>33-36</sup>

Several studies focused on the association of patient attitudes and knowledge with adherence behavior.<sup>37-45</sup> Lerman et al,<sup>10</sup> using a prospective study design, interviewed patients who had missed an initial follow-up appointment and elicited their reasons for nonadherence. The most common reasons included lack of understanding of the purpose of colposcopy, fear of cancer or treatment, forgetting the appointment, and practical barriers (lack of time, money, transportation, or childcare). McKee et al<sup>17</sup> surveyed patients with Papanicolaou smear abnormalities and found multiple factors related to adherence and nonadherence. Remembering being informed of their Papanicolaou smear result and

correct knowledge of the result were associated with adherence, but psychologic barriers, such as fear of cancer, feeling embarrassed during pelvic examinations, and concern about side effects of colposcopy, were not significantly associated with nonadherence.

In summary, the medical literature varies in study design and research focus. Hence, attempts to define consistent barriers to adherence in patients with abnormal Papanicolaou smear findings have had variable results. It is clear, however, that effective communication, higher education level, and more severe abnormalities on Papanicolaou smear are associated with improved adherence.

### ***Adverse Emotional Consequences of Abnormal Papanicolaou Smears***

The patient's response to the abnormal cervical smear result, to its implications, and to the recommended treatment has received attention as a possible barrier to adherence.<sup>32</sup> A number of studies, primarily interview and questionnaire-based investigations of patients, have explored the emotional and psychological consequences of abnormal Papanicolaou smear results.<sup>33,34,36–38</sup> Reelick et al<sup>39</sup> found mild but significant differences in emotional responses of women with positive Papanicolaou smears when compared with women with normal findings on Papanicolaou smears. These differences included feeling somewhat less healthy, less cheerful, and less relaxed. Other aspects of the women's responses, such as optimism, independence, and attractiveness, were not significantly different between groups, however. Women who were concerned about the result before screening and those with more severe dysplasia were more likely to have negative reactions to the abnormal result.

Campion et al,<sup>40</sup> using questionnaires to assess aspects of sexual behavior and responses, found significant emotional reactions after colposcopy and laser ablation for preinvasive disease. With respect to cervical smear results before treatment, no differences were found in sexual behavior or responses in women with abnormal smears when compared with women with normal cytologic findings. A Tennessee study observed 20 women through diagnosis and treatment of cervical intraepithelial neoplasia (CIN), measuring their feelings regarding self and body. The patients in this study reported high levels of concern about possible can-

cer, loss of sexual functioning, and loss of attractiveness.<sup>41</sup> A questionnaire-based rating of 30 women before colposcopy for abnormal Papanicolaou results found extremely high levels of anxiety in these women.<sup>42</sup> Boag et al<sup>43</sup> found significant elevations in overall psychiatric morbidity, anxiety, social dysfunction, and somatic symptoms in patients referred for colposcopy who had a previous history of laser ablation, but not in other patients with abnormal cervical cytologic findings.

Lerman et al<sup>34</sup> found significant elevations in worries about cancer, impairments in mood, daily activities, sexual interest, and sleep patterns in women with abnormal Papanicolaou smear results.<sup>34</sup> Further analysis found an association between impaired mood and nonadherence to colposcopy. Whether the negative emotional responses created a barrier to adherence or whether the responses resulted from the unresolved abnormality was not addressed in the study. Palmer et al<sup>44</sup> determined that the diagnosis of CIN was a "traumatic event" based on significant elevations in intrusive thoughts, avoidance, and state anger, as measured by the Impact of Events and State Trait Anger Scales. Similar elevations in these measures of distress were also found after treatment with laser ablation, indicating that treatment for CIN was also traumatic or that the trauma of diagnosis with CIN persisted several weeks through to the treatment phase.<sup>44</sup>

While working to design an instrument to measure psychosocial effects of abnormal findings on Papanicolaou smears, Bennetts et al<sup>45</sup> conducted in-depth interviews and focus groups to determine areas of concern. Nearly 20% of respondents reported that they were worried "quite a lot" or "very much" that cancer would appear on their body, and more than 10% reported similar levels of concern that they would lose their ability to have a baby.

The described works do not provide direct evidence of these responses creating a barrier to follow-up and treatment for dysplasia. In some studies, differences were found only after treatment for cervical disease, suggesting that the negative emotions could create a barrier to adherence with subsequent positive Papanicolaou smear findings. These considerations aside, the above studies show important emotional responses to cervical cancer screening and treatment, responses that providers must recognize and address at every patient en-



counter to alleviate patient suffering and improve adherence.

### ***Studies Using Intervention Strategies***

If aspects of the patient's age, status, background, or emotional response hinder timely follow-up for abnormal Papanicolaou smear results, determining strategies that assist patients in overcoming these barriers would promote adherence to cervical cancer-screening protocols. Studies have investigated the value of different techniques, including physician reminder systems, patient reminder systems, patient education or counseling, physical or economic barrier reduction, financial incentives, and comprehensive quality control systems (Table 2).<sup>10-16,24,33,35,40,41,46,47</sup> This review focuses on intervention studies with a randomized, controlled trial design.

Paskett et al<sup>16</sup> measured adherence to care of patients who were sent an informative pamphlet designed to motivate women to return for a repeat Papanicolaou smear. These patients were compared with control patients who received a notification letter and an explanation sheet about Papanicolaou smears without the motivational pamphlet. Although a trend toward increased adherence was noted in the group of patients receiving the motivational pamphlet, this trend did not reach statistical significance. In addition, the authors noted that other intervention strategies in the same office (including telephone calls, in-person visits, registered letters) produced a similar improvement in adherence rates.

A randomized trial of low-income inner-city women studied the impact of telephone counseling on patient adherence to colposcopy after abnormal cervical findings.<sup>10</sup> The telephone intervention was designed to address perceived barriers to follow-up through directed counseling. When compared with a control group, patients receiving telephone counseling were significantly more likely to adhere to follow-up colposcopy.

Stewart et al<sup>11,48</sup> also assessed the impact of informational brochures on adherence. The brochures were designed to reduce the emotional distress of patients with abnormal cervical smear findings. Patients receiving these brochures along with appointment reminder letters were compared with a control group who received only reminder letters. Patients in the intervention group completed follow-up at a significantly higher rate than controls

(75% vs 30%). Comparing adherent with nonadherent patients suggested that improvement in patients' understanding of correct follow-up for abnormal Papanicolaou smear results was associated with adherence. Decreased measures of emotional distress did not correlate significantly with improved adherence to care plan.

Miller et al<sup>15</sup> evaluated the use of telephone counseling in enhancing adherence. Using a randomized trial design, low-income, inner-city women who had been informed of an abnormal Papanicolaou smear result were studied. Patients receiving counseling to address psychologic barriers to adherence were compared with patients receiving an appointment reminder by telephone and with a control group that receiving only a letter informing them of the Papanicolaou result and follow-up recommendation. Telephone counseling produced higher adherence rates to initial and repeat colposcopy visits than either the telephone reminder or the letter.

Marcus et al<sup>12</sup> conducted a trial of two different types of interventions. Three study groups were compared with a control group receiving standard care. One group was provided with vouchers for patient transportation, a second was given intensive case tracking with multiple reminders, and a third was both provided with vouchers and given intensive tracking and reminders. Both the economic voucher group and the intensive case tracking group had significant improvement in adherence when compared with standard care control group (71% and 72% vs. 64%, respectively). Interestingly, while the two primary interventions were designed to address separate barriers, combining the two interventions did not lead to increased adherence in addition to either intervention alone. In this regard, it is important to note that all the intervention groups for the above trials had staff contacts with patients of substantially greater number, time, or quality than control groups. Perhaps a timely, sensitive, noncursory telephone call from the patient's primary care provider would be as effective as any of the above interventions.

Segnan et al,<sup>49</sup> conducted an prospective interventional study of 8,385 women randomized into four intervention different groups. Personal invitation letters, with an allocated appointment time, signed by the woman's general physician were found to be most efficacious at increasing adherence to care.

**Table 2. Impact of Interventions on Adherence**

Author(s) Year	Study Type	No.	Interventions	Percent Follow-up Without Intervention	Percent Follow-up With Intervention	P Value
Paskett et al, <sup>16</sup> 1990	Randomized controlled trial	170	Educational pamphlet	51.3	64.2	.10 (NS)
Lerman et al, <sup>10</sup> 1992	Randomized controlled trial	90	Counseling by telephone	43	67	<.05
Stewart et al, <sup>11</sup> 1994	Randomized controlled trial	125	Explanatory brochure	45.8	75.4	.002
Miller et al, <sup>15</sup> 1997	Randomized controlled trial	828	Reminder by telephone	50 initial colposcopies	68 (reminder) initial colposcopies	.01
			Counseling by telephone	30 repeat colposcopies	76 (counseling) initial colposcopies	<.05
					36 (reminder) repeat colposcopies	>.74 (NS)
					61 (repeat counseling) colposcopies	<.05
Marcus et al, <sup>12</sup> 1998	Randomized, controlled trial	1,453	Case tracking	64	72 (tracking & reminders)	<.05
			Reminder by mail		71 (vouchers)	
			Reminder by telephone Economic voucher		71 (tracking, reminders, & vouchers)	
Lauver & Rubin, <sup>33</sup> 1990	Randomized noncontrolled trial	116	Counseling by telephone (trial of counseling methods with alternatively framed messages)	NA	77 (counseling in terms of loss without follow-up)	NS
					71 (counseling in terms of gain with follow-up)	
Marcus et al, <sup>35</sup> 1992	Randomized noncontrolled trial	2,044	Personalized reminder by mail with educational pamphlet Transportation assistance Educational slide-tape program	NA	Not reported	—
Paskett et al, <sup>14</sup> 1995	Observational study	541	Educational pamphlet	34–69 (atypia) 33–88 (dysplasia)	56–81 (atypia) 58–100 (dysplasia)	.03–69 (atypia) .01–.38 (dysplasia)
Block & Branham, <sup>46</sup> 1997	Observational study	147	Case management, tracking Reminders by mail or telephone Physician reminders Transportation assistance	64	87	—
Frisch, <sup>47</sup> 1986	Observational study	206	Case management	37 (within 6 mo) 69 (within 12 mo)	56 (within 6 mo) 89 (within 12 mo)	
Mitchell & Medley, <sup>24</sup> 1989	Observational study	2,372	Physician reminder	NA	82 (atypia, mild dysplasia) 90 (moderate dysplasia)	—
Prislin et al, <sup>13</sup> 1997	Retrospective chart review	76	On-site colposcopy vs referral	73–100	73–80	—

NA: not applicable; NS: not significant.

## Conclusion

The above studies fail to delineate a clear pattern of impediments to follow-up care or specific interventions successful in improving follow-up in a large proportion of patients. This finding does not exclude the importance of emotional, logistic, cultural, or socioeconomic barriers in nonadherence. Rather, it suggests that nonadherence in any individual patient is the result of the interplay of a complex array of these and other factors.

To intervene optimally to promote adherence to care in women with abnormal Papanicolaou smear results, it is important to understand the characteristics of the population where such intervention is planned. Increasing the number and quality of personalized reminders to patients improves follow-up by ensuring clear communication of the cervical smear result, its importance, and the appropriate follow-up care. Such communications should endeavor to elicit and address personally each patient's specific questions and concerns. Focusing efforts on specific nonadherent patients would possibly improve efficiency, but the case management protocol with greatest probability of success in any individual practice would be dictated by that practice's size, structure, and style.

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