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# Understanding Barriers for Adherence to Follow-Up Care for **Abnormal Pap Tests**

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## Understanding Barriers for Adherence to Follow-Up Care for Abnormal Pap Tests

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#### **ABSTRACT**

Objective: Approximately 4000 women annually will die from preventable and treatable cervical cancer. Failure to adhere to follow-up recommendations after an abnormal Pap test can lead to development of cervical cancer. This paper summarizes the body of literature on adherence to follow-up after an abnormal Pap test in order to facilitate development of interventions to decrease morbidity and mortality due to cervical cancer.

Methods: We conducted a comprehensive search of published literature addressing risk factors for adherence or interventions to improve adherence following an abnormal Pap test as the outcome. We included peer-reviewed original research conducted in the United States from 1990 to 2005.

Results: Fourteen analytical and twelve experimental studies that met our criteria were reviewed. Lesion severity and health beliefs were consistently associated with adherence rates. Communication interventions, including telephone reminders, counseling, and educational sessions, increased follow-up compliance across intervention studies. Inconsistent evidence for associations among race, income, and age were found.

Conclusions: Further research is needed to reinforce current studies addressing health beliefs and social support. Interventions that focus on the interplay among psychological, educational, and communication barriers are necessary. These interventions should be adapted and applied across various racial/ethnic and socioeconomic groups to reach all women with a high-risk profile for invasive cervical cancer.

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#### INTRODUCTION

HEN CERVICAL CANCER IS DETECTED EARLY, the likelihood of survival is almost 100% with appropriate follow-up and treatment. Despite the preventable and treatable nature of this cancer, the American Cancer Society (ACS) estimates that almost 4000 women will have died from cervical cancer in 2006 in the United States.<sup>2</sup> A key part of this discrepancy is failure to obtain follow-up care after an abnormal Pap test. The Pap test, which screens for precursor lesions to cervical cancer, is one of the most used cancer screening tools currently available; countrywide estimates from the Behavioral Risk Factor Surveillance System (BRFSS) in 2004 report that 78%-90% of women aged >18 years had a Pap test within the preceding 3 years.<sup>3</sup>

Follow-up diagnostic examinations and, if necessary, treatment are central to the effectiveness of the Pap test in the prevention of invasive cervical cancer.<sup>4</sup> In a recent study of long-term members of a comprehensive medical care program, 13% of invasive cervical carcinomas were attributable to failure to follow up with abnormal Pap test results.<sup>5</sup> With the majority of women adhering to Pap test guidelines, more research is needed to determine why women who receive an abnormal result are not complying with necessary follow-up and treatment schedules.

A large body of literature suggests multiple factors are associated with adherence to follow-up recommendations, including factors associated with the patient, both demographic and psychosocial in nature, and with the healthcare system.<sup>6–9</sup>

The purpose of this systematic review is to summarize reports from recent analytical or experimental research that addressed factors associated with the lack of adequate and timely follow-up care for an abnormal Pap test (nonadherence). The future aim is to facilitate both patient and clinic-based interventions to improve adherence to follow-up recommendations and, thus, reduce needless deaths due to cervical cancer. This is the first review to include both analytical and intervention studies addressing adherence to abnormal Pap test follow-up recommendations and to address risk factors for lack of follow-up by individual, psychosocial, and attributes of the healthcare system.

#### MATERIALS AND METHODS

A systematic approach to all literature was used to identify original research addressing follow-up of an abnormal Pap test. Our review included academic peer-reviewed sources from the following databases: Medline, Pubmed, Science Direct, Medline-Ovid, Med Science, and Ebsco-Medline. The search terms used were: abnormal Pap, colposcopy, Pap test, screening, gynecologist, or cervical cancer, adherence, follow-up, barriers. Reference lists from papers identified were also reviewed for inclusion of additional papers.

To develop a comprehensive review, we included papers published from 1990 to 2005 regardless of whether they had been included in past reviews. The outcome of interest for all papers reviewed was adherence to recommended follow-up care for an abnormal Pap test. In addition, all papers included in the review had to address risk factors for adherence or involve interventions to improve adherence. A total of 73 abstracts were originally identified. Table 1 outlines the criteria for inclusion in this systematic review and the numbers excluded based on these criteria. We required that each study be evidence based, in that the research involved following women either prospectively or retrospectively through follow-up care after an abnormal Pap test (11 excluded). Studies conducted outside the United States were excluded because different systems of medical care are not comparable to that of the United States (n =12). Papers not published in English were also excluded (n = 7). Finally, qualitative research (n = 4), recent reviews (n = 5), and literature older than 1990 (n = 8) were also excluded from this review.

Table 1. Selection of Papers Included in Systematic Review

Inclusion criteria	Number excluded
Total studies originally identified	-73
Evidenced based	-11
Conducted in the United States	-12
English language	-7
Quantitative results	-4
Original research	-5
Published since 1990	-8
Total studies reviewed	26

Defining abnormal Pap tests

For the purposes of this review, an abnormal Pap test includes any result that requires additional diagnostic or follow-up procedures. Therefore, the following Pap test results were considered abnormal: insufficient Pap test, infection, atypia, atypical squamous cells of undetermined significance (ASCUS), low-grade squamous intraepithelial lesions (LSIL), high-grade squamous intraepithelial lesion (HSIL), and atypical glandular cells (AGC).

## Defining adherence

In this review, definitions of adherence varied across studies, but all were evaluated based on follow-up after an abnormal Pap test result within a time period specified by each healthcare office or governing organization.

#### **RESULTS**

Twenty-six papers were identified that met our criteria. 10-35 All studies were quantitative, defined here as a study analyzing data using statistics that reported a p value for correlations and predictors. Table 2 summarizes the key design elements of the 26 quantitative papers that addressed adherence for abnormal Pap test follow-up. The studies are arranged alphabetically by the first author's last name and are presented in two groups by the study design (analytical and experimental studies). Fourteen papers used an analytical study design and addressed risk factors for adherence. 10-14,18-20,23,27-29,31,34 Twelve studies used an experimental or quasiexperimental design: 9 were randomized trials<sup>16,17,24–26,30,32,33,35</sup> and 3 were intervention studies based on nonrandomized designs. 15,21,22 Table 2 provides the study setting and sample, the number of subjects, the data source and list of independent variables assessed, and the data source and operational definition of the outcome (adherence to follow-up recommendations for an abnormal Pap test).

Study sites included public health and community clinics, 11,14,18,19,27–29 hospitals, 13,31 academic clinics, 12,23,34 the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), 10 and a large consortium of laboratories. 20 The sample sizes ranged from 119<sup>23</sup> to 16,132 women. 20

With the exception of four studies that relied on self-report through telephone interviews and questionnaires, <sup>15,27,30,31</sup> all used medical records to obtain data on independent variables. All studies addressed demographic factors as independent variables correlated with adherence; among these were age, race/ethnicity, insurance, marital status, education, income, place of residence, primary language spoken, tobacco use, and cervical lesion severity.

The reviewed research used medical records or self-report to determine adherence and defined adherence as the receipt of recommended follow-up care. However, studies differed in the definition of adherence. Most studies used a restricted time frame <sup>10–12,15,16,18,20,21,23,26,28–30,34,35</sup> that ranged from receipt of follow-up care within 4–6 weeks<sup>35</sup> to receipt of follow-up care within 18 months. <sup>16</sup> Other studies measured adherence by the number of follow-up appointments kept, <sup>14</sup> ever completing the recommended procedure, <sup>19,22,24,25,27,31</sup> or adherence within the time frame set by the physician. <sup>32,33</sup>

Table 3 lists the measures of association, a summary of the study findings, and adherence rates. Adherence rates for the analytical studies ranged from 27%<sup>28</sup> to 90%,<sup>19</sup> whereas those of the experimental studies ranged from 40%<sup>21</sup> to 93%<sup>15</sup> for those receiving the intervention. Nine of twelve intervention studies<sup>15–17,24–26,30,32,35</sup> reported higher adherence among those participating in the intervention. The findings are summarized by patient, healthcare system, and social/environmental characteristics.

#### Patient characteristics

*Age.* Of the 14 studies<sup>10,11,14,16–18,20,23–27,31,34 that addressed age and adherence, 7 found that younger women were less likely to receive follow-up care. <sup>16,17,20,25–27,34</sup> Specifically, McKee et al.<sup>27</sup> reported that teenagers and women older than 30 were less likely to receive follow-up care. Additionally, a study conducted by Fox et al.<sup>18</sup> reported that increased age was a significant risk factor for noncompliance.</sup>

Race/ethnicity. Of the 10 analytical 10-12,14,18,23,27,28,31,34 and 7 experimental 16,17,24-26,30,32 studies to address race/ethnicity and adherence, 710,11,17,18,25,26,32 found that African American women were less likely to schedule follow-up visits, to keep appointments,

Descriptions of Original Research Addressing Adherence to Follow-Up Care for Abnormal Pap Test (n = 26)TABLE 2.

Author, date	Setting/sample	Study design	Sample size	Independent variables source and list	Outcome source and definition
Analytical studies as Bernard et al., 2005 <sup>10</sup>	Analytical studies addressing risk factors for adherence Bernard et Nationwide, women with 2 al., 2005 <sup>10</sup> abnormal Pap tests within 2 years enrolled in the NBCCEDP <sup>2</sup> , 1991–2000	e Retrospective cohort	10,004	Source: Medical record Variables: Age, race, lesion severity	Source: Medical record Outcome: Followed up within the 2-year observation period
Cardin et al., 2001 <sup>11</sup>	Houston, TX Health Department, women with abnormal Pap test, 1996–2000	Retrospective cohort	1,216, 24% HSIL, 76% LSIL	Source: Medical record Variables: Age, race, lesion severity.	Source: Medical record Outcome: Completed referral evaluation/currently evaluated/treated within 9 months of abnormal Pap test
Carey and Gjerdingen, 1993 <sup>12</sup>	St. Paul, University of Minnesota Family Practice Clinic, women with an abnormal Pap test: 1989–1992	Retrospective cohort	190	Source: Medical record Variables: Race.	Source: Medical record Outcome: Followed up by 1992
Crane, 1996 <sup>13</sup>	Los Angeles, C <sup>'</sup> A, two county hospitals, women with abnormal Pap test, 1986–1988	Cohort	498	Source: Medical record interview Variables: Social support, knowledge.	Source: Medical record interview Outcome: Followed up within 4 months of abnormal Pap test
Eger and Peipert, 1996 <sup>14</sup>	Providence, RI, Women and Infants Colpocopy Clinic, women referred for colposcopy, 1992–1993	Retrospective case-control	179	Source: Medical record Census Variables: Age, race, insurance, lesion severity, marital status, tobacco use, gravidity, parity, income (ZIP code)	Source: Medical record Outcome: Number of appointments kept or missed
Fox et al., 1997 <sup>18</sup>	CA breast and cervical cancer control program, women with abnormal Pap test, 1994	Retrospective cohort	1,738	Source: Medical record Variables: Age, race, Jesion severity, rural residence.	Source: Medical record Outcome: Followed up at least 60 days after abnormal Pap test
Hartz and Fenaughty, 2001 <sup>19</sup>	Anchorage, AK reproductive health clinic, low-income women with CIN1, 1995–1999	Cohort	219	Source: Medical record Variables: Management choice (cryotherapy vs. serial Pap), income.	Source: Medical record Outcome: Completion of follow-up
Jones and Novis, $2000^{20}$	American College of Pathologists Q-Probes program, women with abnormal cytology, 1998	Retrospective cohort	16,132; 306 laboratories; 60 cases per laboratory	Source: Medical record Variables: Age, lesion severity, pregnancy status, laboratory characteristics	Source: Medical record Outcomes: Followed up within 1 year of abnormal Pap test
Lavin et al., 1997 <sup>23</sup>	Boston, MA departments of pediatric and obstetrics and gynecology, adolescents with abnormal Pap tests, 1994–1995	Retrospective cohort	119	Source: Medical record Variables: Age, race, insurance, lesion severity, previous referral	Source: Medical record, telephone Outcome: Completion of follow-up

Source: Telephone survey, medical record Outcome: Completion of colposcopy	Source: Medical record Outcome: Percent of women receiving colposcopy or repeat Pap tests every 6 months until 3 are normal	Source: Medical record Outcome: Followed up within 8 months of abnormal Pap test	Source: Medical record Outcome: Delay in first scheduled clinic visit for follow-up or multiple contacts needed to	Source: Medical record/pathology Outcome: Followed-up within 4 months of abnormal Pap test for HSIL and 7 months for LSIL	Source: Medical record report Outcome: Completed clinic appointments during 1-year study period (partial, full, or nonadherent)	Source: Medical record Outcome: Followed up within 6 months of abnormal Pap test and completed diagnostic resolution in 18 months
Source: Questionnaire Variables: Age, race, insurance, lesion severity, education, communication, psychological, provider,	Source: Medical record Variables: Race, insurance, lesion severity, pregnancy status, provider training, colposcopy on site,	discussion of care plan Source: Medical record Variables: Lesion severity, insurance, languge, proximity to clinic	Source: Mail/phone survey Variables: Age, race, education, income, health beliefs, cancer knowledge	Source: Medical record Variables: Age, race, lesion severity, insurance, primary language, provider type, source of care	Source: Phone questionnaire Variables: Access to care, knowledge, health beliefs, depression, anxiety. Intervention: Stepped care with mental health assessment (case management addressing reminders, knowledge, psychosocial factors, and	system barriers) Source: Medical record Variables: Age, race, insurance status, lesion severity Intervention: Case management (reminder protocol) and universal colposcopy vs. traditional care.
279	387	243	1,049	423	196	108
Telephone survey	Retrospective cohort	Retrospective cohort	Cohort	Retrospective cohort	ence Intervention	Randomized trial
Bronx, NY, Montefiore Family Health Center, women with an abnormal Pap test; 1993–1994	7 urban community health centers, women with abnormal Pap test, 1996	CA Family Planning Clinics, women with abnormal Pap tests referred for colposcopy, 1994–1996	Los Angeles, CA, Kaiser Permanente Medical Center, women with abnormal Pap test,	Boston, MA urban academic clinics, women with abnormal Pap test, 1999–2000	Experimental studies addressing risk factors for adherence Ell et al., Los Angeles, CA,  2002 <sup>15</sup> Screening Adherence Follow-up Program (SAFe),  women with LSIL/HSIL, 1998–2000	Oakland, CA, Alameda County Medical Center ER, women 18–74 with an abnormal Pap test, October 1993–June 1995
McKee et al., 1999 <sup>27</sup>	McKee et al., 2001 <sup>28</sup>	Melnikow et al., 1999 <sup>29</sup>	Nelson et al., 2002 <sup>31</sup>	Peterson, et al., 2003 <sup>34</sup>	Experimental studies Ell et al., 2002 <sup>15</sup>	Engelstad et al., 2001 <sup>16</sup>

Table 2. Descriptions of Original Research Addressing Adherence to Follow-Up Care for Abnormal Pap Test (N = 26) (Cont'd)

Author, date	Setting/sample	Study design	Sample size	Independent variables source and list	Outcome source and definition
Engelstad et al., 2005 <sup>17</sup>	Oakland, CA, Alameda County Medical Center ER, women 18–74 with abnormal Pap test, Sentember 1999–Amoust 2001	Randomized trial status	348	Source: Medical record Variables: Age, race, insurance status, lesion severity, language, obstetrical	Source: Medical record Outcome: Initial follow-up within 6 months of abnormal Pap test
				Intervention: Community health advisor (addressing reminders, knowledge, psychosogial factors)	
Kaplan et al., $2000^{21}$	Los Angeles, CA, hospitals and health care centers, women with abnormal Pap test, 1989–1990	Intervention	4,488	Source: Medical record and data system Intervention: Tracking follow-up, transportation and financial incentives	Source: Medical record/data system Outcome: Followed up within 9 months of abnormal Pap test; categorized as complete, partial,
Lacey et al., 1993 <sup>22</sup>	Chicago, IL community-based health clinic, women with abnormal Pap test,	Intervention	101	Source: Medical record Intervention: Referral to public hospital vs. private physician	Source: Telephone call to private physicial OR computerized tracking system Outcome: Completed scheduled follow-in amointment
Lerman et al., 1992 <sup>24</sup>	Philadelphia, PA, Temple University Hospital, low-income minority women who missed a colposcopy	Randomized trial	06	Source: Medical record Variables: Age, race, marital status, education Intervention: Telephone counseling (addressing knowledge, psychosocial	Source: Medical records, validated by telephone interview Oucome: Compliance with rescheduled colposcopy
Marcus et al., 1992 <sup>25</sup>	Los Angeles, CA, 12 primary healthcare clinics, women with abnormal Pap test, 1984–1986	Randomized trial	2,044	Source: Medical record Variables: Age, race, insurance, lesion severity, marital status, education Interventions (1) letter (2) tape on Pap tests (3)	Source: Medical record, telephone interview, mail questionnaire Outcome: At least one return visit vs. no return visit
Marcus et al., 1998 <sup>26</sup>	Los Angeles, CA, County Department of Health Services, women with abnormal Pap test	Randomized trial	1,453	uansportation incentives Source: Medical record Variables: Age, race, lesion severity, live-in relationship, insurance, hospital Interventions: (1) reminder+ pamphlet (2) voucher	Source: Medical record and telephone interview Outcome: Followed-up within 4–6 months after abnormal Paptest

Source: Sign-in list at clinic Outcome: Followed up within 6 months after abnormal Pap test	Source: Medical record Outcome: Obtained repeat Pap by date specified by physician	Source: Medical record Outcome: Followed-up within 1 week of date specified by physician	Source: Medical record Outcome: Followed-up within 4– 6 weeks after abnormal Pap test
Source: Telephone interview Variables: Race, marital status, education. Intervention: Telephone counseling and reminder protocol (addressing knowledge, psychosocial	Source: Medical record Intervention: Pamphlet	Source: Medical record Variables: Race, lesion severity, number of children, smoking status Intervention: Motivational brochures	Source: Medical record Intervention: Video or traditional colposcopy
828	161	541	09
Randomized trial	Randomized trial	Randomized trial	Randomized trial
Philadelphia, PA, Temple University Hospital, women with abnormal Pap test, 1992– 1995	Seattle, WA, Women's Care Center, women with abnormal Pap tests. 1987–1988	6 clinics: 2 family planning, 2 dysplasia, 2 family practice	Miami-Dade County, FL colposcopy clinic, women with abnormal Pap test, June 2002– December 2002
Miller et al., 1997 <sup>30</sup>	Paskett et al., 1990 <sup>33</sup>	Paskett et al., 1995 <sup>32</sup>	Takacs et al., 2004 <sup>35</sup>

<sup>a</sup>HSIL, high-grade squamous intraepithelial lesion; LSIL, low-grade squamous intraepithelial lesion; STI, sexually transmitted infection; NBCCEDP, National Breast and Cervical Cancer Early Detection Program.

Table 3. Summary of Results of Original Researach Addressing Adherence to Recommendations for Follow-Up Care for Abnormal Pap Test (N = 26)

Measure of association and confidence interval or p value

Author, date

Adherence rate

Summary of findings

Analytical studies address Bernard et al., 2005 <sup>10</sup>	Analytical studies addressing risk factors for adherence  Bernard et al., Adherence $2005^{10}$ After 2 abnormal Pap tests; race: $p=0.01$ ASCUS-ASCUS: <sup>a</sup> 23%, no follow-up  ASCUS-LSIL: 12.4%, no follow-up	African Americans had a higher percentage of no-follow up compared with other racial groups Those with ASCUS on second Pap test result were less likely to follow up than those with LSIL	72.3%
Cardin et al., 2001 <sup>11</sup>	Appointment scheduling African American vs. other race: OR = 0.47, 0.33–0.67 Adherence African American vs. other race: OR = 0.55, 0.41–0.75	African Angerican women with ASCUS/LSIL were less likely to be compliant than women of other races Women with LSIL were less likely to be compliant than women with HSIL	62%
Carey and Gjerdingen, 1993 <sup>12</sup>	Follow-up rate difference Asian vs. whites: $p < 0.001$ ; Asian vs. African American: $p < 0.05$	Southeast Asian women were less likely than white and African American women to comply with follow-up	86.3% diagnostic 79.5%: treatment
Crane, 1996 <sup>13</sup>	Adherence By support: any social support; OR = $3.12$ , $\rho$ < $0.001$ By knowledge:	Women who received informational, emotional, and/or tangible support were more likely to be compliant Women who had less Pap test knowledge were less likely to adhere to recommendations	%29
	Informational support, OR = 1.88, $p = 0.03$ Knowledge of Pap test: OR = 1.92, $p = 0.003$ By race/ethnicity All: Emotional support, $p = 0.01$ Latinas: Tangible support, $p < 0.05$ African Americans: Emotional support, $p < 0.05$	Latinas who received tangible support and African Americans who received emotional support were more likely to comply	
Eger and Peipert, 1996 <sup>14</sup>	Adhrence Lesion grade: OR = $0.34$ , $p = 0.01$	Women who were noncompliant were less likely to have high-grade histology than women who were compliant Age, race, insurance, marital status, tobacco use, gravidity, parity, income were not associated with adherence	77%
Fox et al., 1997 <sup>18</sup>	Nonadherence Urban vs. rural, OR = 1.73, $p < 0.006$ African American vs. white, OR = 3.80, $p < 0.001$ Asian vs. white, OR = 1.94, $p < 0.009$ Hispanic vs. white, OR = 1.84, $p < 0.001$ SIL vs. negative, OR = 9.43, $p > 0.001$	Increased age, nonwhite race/ethnicity, urban setting, and severity of Pap test result are significant pedictors of not completing follow-up	35.6%
Hartz and Fenaughty, 2001 <sup>19</sup>	Adherence First follow-up visit Surveillance vs. cryotherapy, $p=0.01$ High income vs. low income, $p=0.008$	Patients who chose surveillance only were more likely to adhere to initial recommendations but not for long-term follow-up Women who had highest mean income had highest completion of follow-up rate	90%: 1st visit after colposcopy 37%: complete

85%: 12 months 77%: 6 months 65%: 3 months 61.7%	75%	27%: complete 28%: moderate	56%	87%: timely 13%: delayed	62%	83%: overall 93%: HSIL (continued)
Women with HSIL/CIN were more likely to receive follow-up than women with LSIL or GIL  Younger and pregnant patients were less likely to receive follow-up Visit to an adolescent clinic predicted adherence No differences in race, insurance status, age, Pap test results, recommendations for previous colposcopy or Pap tests for	compliers vs. noncompliers  Teenagers were less likely to receive follow-up care, as well as women older than 30  Lack of effective communication was associated with low rates of return for colposcopy Pap test severity, ethnicity, insurance, and education were not significant predictors of adherence No psychological, logistical, or provider characteristics were	associated with barriers to colposcopy Severity of lesion, availability of colposcopy on site, discussion of plan and site predicted adherence Ethnicity, insurance, provider training, and pregnancy were	not associated with adherence Women with LSIL/HSIL were less likely to adhere to colposcopy compared with repeat Pap tests Women with ASCUS were more likely to adhere to colposcopy compared with repeat Pap tests Women with ASCUS were less likely to adhere than all others to any appointment Women with no insurance were less likely to follow up	Proximity to clinic and language did not predict adherence When fatalism and health beliefs were included in model, race/ethnicity was n ot related to delay in care Women who delayed care had higher mean fatalism score Women who believe a Pap test is needed only with abnormal bleeding were more lilkely to delay care Income, education, and race were not associated with delays in come.	Young age and either having Medicaid or beiing uninsured was a significant preadictor of inadequate follow-up Neither race/ethnicity, specialty of provider, language, nor lesion severity were significant predictors of inadequate follow-up	Women enrolled in program had significantly better adherence rates than nonenrollees Barriers to care cited included fear of finding cancer, costs,
Adherence HSIL/CIN vs. LSIL/GIL, $p = 0.001$ Pregnant < nonpregnant, $p < 0.01$ Adherence Adolescent clinic visit vs. no visit, $79\%$ vs. $455$ , $p = 0.007$	Adherence rate Age, $p = 0.02$ ; Pap test severity, $p = 0.06$ Knowledge of results, $p = 0.001$ Recall receiving letter, $p = 0.001$ Doctor understands my needs, $p = 0.03$		Adherence Colposcopy vs. repeat Pap test LSIL/HSIL, HR = 0.37 (0.14–0.99) ASCUS, HR = 2.67 (1.22–5.86) Adherence to any appointment LSIL/HSIL vs. ASCUS, HR = 3.59 (1.40–9.25)	No insurance, HR = 0.43 (0.20–0.93) Delay in care Need a Pap test only with abnormal bleeding (yes/no), OR = 1.1 (1.1–15.5) Fatalism score/point increase, OR = 1.1 (1.0–1.2)	Inadequate follow-up Adjusted OR (95% CI) Age 18–29 vs. ≥50 = 2.7 (1.1–6.4) Medicaid vs. HMO = 1.9 (1.0–3.5) Uninsured vs. HMO = 1.6 (0.9–2.9) Adjusted HR, ≤30 years = 0.6 (0.4–0.9) Uninsured = 0.8 (0.6–1.0)	Experimental studies addressing fisk factors for adherence Ell et al., 2002 <sup>15</sup> Adherence LSIL-dichotomous: OR = 3.14 (1.5–7.7)
Jones and Noves, 2000 <sup>20</sup> Lavin et al., 1997 <sup>23</sup>	McKee et al., 1999 <sup>27</sup>	McKee et al., 2001 <sup>28</sup>	Melnikow et al., $1999^{29}$	Nelson et al., 2002 <sup>31</sup>	Peterson et al., 2003 <sup>34</sup>	Experimental studies add Ell et al., 2002 <sup>15</sup>

Author, date	Measure of association and confidence interval or p value	Summary of findings	Adherence rate
Engelstad et al., 2001 <sup>16</sup>	Incremental adherence: 41% full, 42% partial, 17% nonadherent HSIL-dichotomous: OR = 6.5 (2.5–16.9) Incremental adherence: 61% full, 42% partial, 17% nonadherent Adherence Intervention: OR = 3.98 (1.63–9.74) Age: OR = 1.08 (1.02, 1.13) Race: Asian, OR = 0.16 (0.03–0.85) No insurance: 2.78 (1.00–7.71) Adherence and resolution Intervention: OR = 6.53 (2.39–17.84)	worries about examination treatment, lack of understanding of follow-up examination, and transportation or child care problems  The proportion of women who received initial follow-up or diagnostic resolution was greater in the iinterventional arm Older women, those without insurance, and non-Asian women were more likely to follow up in 6 months Non-Asian women and all women with less severe lesions (ASCUS/AGUS) were more likely to follow up in 6 months and have diagnostic resolution in 18 months	50%: intervention 19%: control
Engelstad et al., 2005 <sup>17</sup>	Kace: Asian, OK = 0.00 (0.01-0.01) HG/LGSIL vs. $ASC/AGUS$ : OR = 4.24 (1.21-14.81) Adherence Overall intervention: OR = 3.33, p = 0.001 Age: OR = 1.04, $p = 0.001$ Race: white; OR = 3.3, $p = 0.001$ ; Asian: OR = 0.3, $p = 0.03$	Adherence to follow-up was greater in the intervention arm overall and by all lesion types Older women and white women were more likely to follow-up than African Americans, Asians were less likely to follow-up than African Americans Language, Jesion severity, insurance, Hispanic race, and	60.7%: intervention 32.4%: control
Kaplan et al., 2000 <sup>21</sup>	Adherence: Baseline vs. all intervention years Hospital, OR = 2.74 (0.75–10.00) CHC, OR = 2.28 (0.47–11.13)	obstetrical status were not associated with adherence No significant difference in follow-up among control and intervention groups by location of treatment: hospitals, CHC, or PHC	40%: intervention 35.6%: control
Lacey et al., 1993 <sup>22</sup>	PHC, OR = 1.61 (0.17–14.90) Adherence Rate of adherence: public hospital vs. private physician, $p > 0.05$	No difference in follow-up rates occurred between women who were referred to public hospial and those who chose to follow-up with their private physician	69%: overall 70%: public hospital
Lerman et al., 1992 <sup>24</sup>	Adherence Intervention: OR = 2.6 $p < 0.003$	No SES factors were associated with adherence; telephone intervention improved adherence for colposcopy Half of all nonadherer's reported the reason for missing	57%: private 43%: control 67%: intervention
Marcus et al., 1992 <sup>25</sup>	Adherence Race/ethnicity: $p < 0.02$ ; age: $p < 0.001$ ; education: $p < 0.01$ ; insurance; $p < 0.01$ ; health care: $p < 0.001$ ; severity of Paptes: $p < 0.001$	appointment was not knowing purpose of test African American, Hispanic, younger patients, patients with less than HS education, those with no insurance, using a county facility, or those with a less severe Pap test result were less likely to return for follow-up care Transportation incentives had significant impact on county patients, those with more severe Pap tests, and noninsured	Ranged 56%–87% based on clinic site 71%: overall

ssəl	70% for m	e 60%	51.3%: control 64.2%: intervention	33.8%-69.3%: atypia 33.3%-87.5%:	50%: control 80%: intervention
Personalized follow-up with slide-tape program had significant impact on noncounty patients and those with less severe Pap test results	Interventions had significant and independent effect on follow-up rates African American women were less likely to return for follow-up care than white women Women in a live-in relationshiip vs. no live-in relationship and those with HSIL vs. LSIL were more likely to return for follow-up care Younger women were less likely than older women to return for for follow-up care	Women with standard care were not predicted of address those who had telephone confirmation; those with telephone confirmation were less likely to adhere than those with telephone counseling  Forgetting appointments and conflicts were both independently associated with nonadherence  No socioeconomic variables were associated with adherence	Intervention pamphlets increased compliance in 13% of women who would have been noncompliers, but difference was not statistically significant at the $p=0.05$ level	Significant predictors of adherence were being in intervention clinic, having dysplasia, and being white, a nonsmoker, and nulliparous	Patients undergoing video colposcopy were almost 5 times more likely to return for follow-up than patients undergoing regular colposcopy
Noncounty patients: personalized follow-up with slide-tape program, OR = 4.54 (1.12–18.40) Severe Pap tests: incentive: OR = 1.71 (1.10–2.67) Less severe Pap test: personalized follow-up with slide-tape program, OR = 5.16 (1.47–18.04) No insurance: incentive OR = 1.77	Risk of returning for follow-up care Follow-up intervention: OR = 1.56 (1.12–2.17) Voucher intervention: OR = 01.50 (1.09–2.05) Age: OR = 1.03 (1.02–1.05) Live-in relationship (yes/no): OR = 1.54 (1.22–1.95) African VS. white: OR = 0.49 (0.27–0.90)	Adherence Standard care vs. telephone confirmation: OR = 0.47 (0.32–0.73)  Telephone counseling vs. telephone confirmation: OR = 1.50 (1.04–2.17)  Forgets appointments: OR = 0.31 (0.19–0.51) Scheduling conflicts: OR = 0.45 (0.25–0.72)	Adherence Compliance rate: control = 51%, intervention = 64%, OR = 1.71 (0.91–3.20) $v = 0.10$ (two tailed)	Adherence Intervention: OR = 2.6, 1.2–5.6 Dysplasia vs. atypia: OR = 4.2, 1.4–12.3 White vs. African American: OR = $3.0 (1.1–7.9)$ Nonsmoker vs. smoker: OR = $2.5 (1.3–5.7)$ Nulliparou: OR = $2.9 (1.1–8.2)$	Adherence Rate of follow-up: video vs. resular colposcopy = 80% vs. 50%, p = 0.014, adjusted OR = 4.9, 95% CI = 1.2-19.4
	Marcus et al., 1998 <sup>26</sup>	Miller et al., 1997³0	Paskett et al., 1990 <sup>33</sup>	Paskett et al., 1995 <sup>32</sup>	Takacs et al., 2004 <sup>35</sup>

<sup>&</sup>lt;sup>a</sup>AGUS, atypical glandular cells of undetermined significance; ASCUS, atypical squamous cells of undetermined significance; CHC, community health clinics; CIN, cervical intraepithelial neoplasia; GIL, glandular epithelial lesion; HMO, health maintenance organization; HSIL, high-grade squamous intraepithelial lesion; LSIL, low-grade squamous intraepithelial lesion; OR, odds ratio; PHC, provider health clinics; SES, socioeconomic status.

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or to receive follow-up care. Specifically, Cardin et al.<sup>11</sup> reported that African American women with ASCUS/LSIL were less likely to be compliant than African American women with HSIL. Four studies<sup>12,16–18</sup> reported that Asian women were less likely than women of other race/ethnicities (whites or African Americans) to comply with follow-up recommendations. Finally, two studies found that Hispanics were significantly less likely to adhere to follow-up recommendations than white<sup>18</sup> and African American women.<sup>25</sup> However, the only study to address fatalism and health beliefs,<sup>31</sup> reported that race/ethnicity was no longer associated with adherence after adjusting for these factors.

*Primary language*. All three studies that investigated a primary language other than English as a barrier to follow-up care<sup>17,29,34</sup> concluded that this demographic was not associated with adherence.

Place of residence. Two studies examined place of residence by assessing urban vs. rural residence<sup>18</sup> and proximity to clinic.<sup>29</sup> Proximity to clinic was not a predictor of adherence,<sup>29</sup> but urban setting was a significant predictor of nonadherence.<sup>18</sup>

Education. Five studies investigated educational attainment, measured by receipt of a high school diploma, <sup>24,25,27,30,31</sup> as a predictor of adherence to follow-up care. Only one study found that those with less than a high school education were less likely to return for follow-up care. <sup>25</sup>

*Pregnancy status*. Three studies addressed pregnancy status and adherence<sup>17,20,28</sup>; only and Novis<sup>20</sup> reported that pregnant women were less likely to receive timely follow-up. Gravidity and parity were not associated with adherence in one study,<sup>14</sup> although being nulliparous was positively associated with being adherent in another.<sup>32</sup>

Tobacco use. Two studies that assessed tobacco use as a predictor of adherence to follow-up found conflicting results. Eger and Peipert<sup>14</sup> found that tobacco use was not associated with the number of follow-up appointments kept, whereas, Paskett et al.<sup>32</sup> found that nonsmokers were more likely than smokers to follow up within 1 week of the date specified by the physician.

*Income/insurance/cost of follow-up*. Thirteen studies addressed income, <sup>14,19,31</sup> insurance, <sup>14,16,17,23,25–29,34</sup>

or cost as barriers to receiving follow-up care. 21,25,26 Four found that those with higher income<sup>19</sup> or private insurance<sup>25,29,34</sup> were more likely to adhere to recommended follow-up. Conversely, Engelstad et al. 16 found that women with no insurance were more likely to have a followup visit in 6 months than those with insurance. The remaining eight studies found no association between adherence and income<sup>14,21,31</sup> or insurance. 14,17,23,26-28 Of three interventions 21,25,26 to address economic strain, however, two reported that transportation incentives<sup>25</sup> and economic vouchers had a significant impact on adherence.<sup>26</sup> Furthermore, cost, transportation, and child care problems were among the most frequent barriers reported by others. 15,24,30

Knowledge of Pap test. Several studies addressed the influence of Pap test knowledge on adherence to follow-up. 13,15,17,24-26,30-33 Both Crane 13 and Nelson et al.<sup>31</sup> found that women who did not know the purpose of a Pap test were less likely to adhere to recommendations than those who correctly identified the purpose. Two studies that investigated barriers to care reported that lack of understanding of the purpose of a follow-up examination was a reason for nonadherence. 15,24 Studies that used educational brochures<sup>26,32,33</sup> or a tape on Pap tests<sup>25</sup> all reported a significant increase in compliance. Telephone counseling interventions, including education on abnormal Pap tests and the importance of follow-up, also predicted adherence. 15,17,24,30 Finally, Lavin et al. 23 found that a visit to an adolescent clinic positively predicted adherence; the authors speculated that during this visit, more information on the purpose and importance of follow-up care may have been given.

Lesion severity. Of the 15 studies that addressed lesion severity and adherence, 10,11,14,16-18,20,23,25-29,32,34 11<sup>10,11,14</sup>,16–18,20,25,26,28,29,32 found that women with less severe lesions were less likely to adhere to followup recommendations. Melnikow et al.<sup>29</sup> reported that, overall, women with LSIL/HSIL were more likely to adhere to any appointment compared with women with ASCUS; however, women with LSIL/HSIL were less likely to adhere to colposcopy compared with repeat Pap tests, whereas women with ASCUS were more likely to adhere to colposcopy compared with repeat Pap tests. When following women after two abnormal Pap tests, Benard et al. 10 stated that women whose results were less severe on the second assessment were least likely to receive the recommended colposcopy.

Psychosocial factors

Psychological barriers. When addressing health beliefs and adherence, Nelson et al.<sup>31</sup> found that fatalism and health beliefs (specifically, that Pap tests were needed only when one had abnormal bleeding) were associated with poor adherence. Another study addressed psychological factors, including fear of cancer, embarrassment of pelvic examinations, and belief in early detection and follow-up. Researchers reported no significant differences in adherence among women who differed in responses on these items.<sup>27</sup> Four intervention studies used a case management approach to address psychosocial factors, including attitudes, coping skills, anxiety, and fear resulting from an abnormal Pap test result. 15,17,24,30 Psychological barriers to care reported by women in each study included fear of finding cancer, worries about examination/treatment, and fertility concerns. All interventions addressing these concerns resulted in significant differences in adherence; women in the intervention group in each respective study were more than twice as likely to follow up as women in the control group. 15,17,24,30

Social support. Six studies addressed social support and marital status or live-in relationship as a predictor of adherence to follow-up after an abnormal Pap test. <sup>13,14,24–26,30</sup> Two found that women with a live-in relationship<sup>26</sup> or those with any type of social support<sup>13</sup> were more likely to follow up within 4–6 months than those without a live-in relationship or any kind of social support. Crane. <sup>13</sup> found that the type of support most likely to affect adherence differed by ethnic group. African American women were more likely to adhere when emotional support was available, whereas tangible support significantly influenced adherence among Latinas. <sup>13</sup>

#### Healthcare system characteristics

A number of studies assessed the relationship of adherence to existing clinician and site characteristics, including appointment reminder protocols. <sup>15–17,19–22,26–28,30,34,35</sup>

Patient involvement/communication. Clinician involvement of patients in decisions, referrals, and management options were assessed in two studies. <sup>19,28</sup> Hartz and Fenaughty <sup>19</sup> reported that patients who chose surveillance had improved initial adherence but not long-term adherence. McKee et al. <sup>28</sup> reported that discussion of follow-

up options and plans at a prior visit increased adherence rates. Communication between clinicians and patients was also noted as a factor influencing adherence to follow-up. Lack of effective communication was associated with lower rates of adherence in one study,<sup>27</sup> as both "knowledge of results" and "getting the doctor to understand my needs" were significantly associated with adherence in univariate analysis.

Healthcare facility/clinician specialty. Site attributes were also assessed as an indicator of adherence to follow-up in some studies. McKee et al.<sup>28</sup> reported that clinics with colposcopy on-site had higher adherence rates. Takacs et al.<sup>35</sup> reported that patients randomized to the video colposcopy were five times more likely to return for followup care relative to those receiving traditional colposcopy. Lacey et al.<sup>22</sup> reported no difference in follow-up rates between women who were referred to the public hospital and those who chose to follow up with their private physician. Furthermore, three studies<sup>27,28,34</sup> found that clinician specialty was not associated with improved adherence. The only study to address laboratory characteristics<sup>20</sup> reported no association between adherence and the type of follow-up system used by clinics, laboratory reporting summaries, or the proficiency of cytologists in reading slides.

Reminder protocols. Several experimental studies included protocols in which the healthcare facility called or sent a reminder letter approximately 1 week before the woman's appointment for follow-up care. 15–17,21,26,30 Five 15–17,26,30 of six studies reported a positive association between the reminder protocol and adherence to follow-up care; three of the studies were coupled with telephone counseling or an educational pamphlet. 15,17,26 Miller et al. 30 reported that the telephone reminder system was effective at increasing adherence rates, but not as effective as additional telephone counseling. The only study to report no change in adherence used a letter instead of a telephone reminder system. 21

Strengths and limitations of reviewed research

Table 4 outlines the strength and quality of studies reviewed and provides a corresponding score based on the following categories: power/sample size, use of a theoretical model, study design, response rate, outcome validation, and measurement of lesion severity. Studies that used a

QUALITY OF STUDIES REVIEWED FOR BARRIERS TO ADHERENCE TO FOLLOW-UP CARE FOR ABNORMAL PAP TESTS TABLE 4.

Total score (Points/total)	8/12 = 0.67b $8/12 = 0.67b$ $4/12 = 0.33$ $8/14 - 0.57$			8/14 = 0.57 9/14 = 0.64 11/14 = 0.78 8/14 = 0.57 7/14 = 0.50 13/14 = 0.92 12/14 = 0.92 11/14 = 0.92
Measurement of lesion severity 0 = All lesion levels combined 1 = Separate analysis by lesion severity	1100	0000	0 0 1 1 0	1110011111
Outcome validation 0 = Self- report 1 = Medical record 2 = Validation		1	I	7
Response rate $0 = None$ , or $>50\%$ $1 = 50\%-70\%$ $2 = 70\%+$	$\frac{NA^a}{NA^a}$ $\frac{NA^a}{1}$	$\stackrel{\Lambda}{N}_{A^a}^{A^a}$ $\stackrel{\Lambda}{N}_{A^a}^{A^a}$ $\stackrel{\Lambda}{N}_{A^a}^{A^a}$	$\stackrel{\circ}{NA^a}$ $\stackrel{\circ}{NA^a}$ $\stackrel{\circ}{NA^a}$	000000000000
Study design $0 = Case series$ $1 = CC/CS$ $2 = Cohort$ $3 = Intervention$ $4 = RCT$	0000	1-0000-	. 4 4 4 4 4	ი ძ ი ი ძ ძ ძ ძ ძ ძ ი თ ი ი თ ძ ძ ძ ძ ძ ძ
$Theoretical \\ model \\ 0 = No \\ 1 = Yes$	0 0 0 -	,00000	0 0 1 0	1 0 1 0 1 1 0 0 1 1 0 0 1 1 1 0 0 1 1 1 0 1
Power/ $sample\ size$ $0 = <100$ $1 = 100-399$ $2 = 400-699$ $3 = 700-999$ $4 = 1000+$	4410	l — ಈ — ಈ — —	1 1 1 4 0	
Author, year	Analytical studies Bernard et al., 2005 <sup>10</sup> Cardin et al., 2001 <sup>11</sup> Carey and Gjerdingen	Eger and Peipert, 1996 <sup>14</sup> Fox et al., 1997 <sup>18</sup> Hartz and Fenaughty, 2001 <sup>19</sup> Jones and Hovis, 2000 <sup>20</sup> Lavin et al., 1997 <sup>23</sup> McKee et al., 1999 <sup>27</sup>	McKee et al., 2001 <sup>28</sup> Melnikow et al., 1999 <sup>29</sup> Nelson et al., 2002 <sup>31</sup> Peterson et al., 2003 <sup>34</sup> Experimental studies	Éll et al., 2002 <sup>15</sup> Engelstad et al., 2001 <sup>16</sup> Kaplan et al., 2000 <sup>21</sup> Lacey et al., 1993 <sup>22</sup> Lerman et al., 1992 <sup>24</sup> Marcus et al., 1998 <sup>26</sup> Marcus et al., 1998 <sup>36</sup> Miller et al., 1997 <sup>30</sup> Paskett et al., 1990 <sup>33</sup> Paskett et al., 1997 <sup>33</sup> Takacs et al., 2004 <sup>35</sup>

 $^aRetrospective$  study; no applicable response rate (total score out of 12 points).  $^bHigh\mbox{-}quality$  study (score  $\ge 0.67$  or top 33% of studies).

retrospective cohort design were not considered when assessing response rates.  $^{10-12,14,18,20,23,28,29,34}$  Therefore, the total score was out of 14 points for those with a response rate and 12 points for those without a response rate. Studies that scored within the top third of the sample were determined to be of high quality (score  $\geq$  0.67) (Table 4)  $^{10,11,17,18,20,21,25,26,30-32}$ 

Sample size indicates study power and the ability to correctly rule out the possibility that a type 2 error occurred (not having sufficient power to detect a true association). Study power is, however, a function of sample size, the prevalence of the independent variable, and the prevalence of the outcome in the study population. Among the reviewed research, nine had good study power. <sup>10,11,18,20,21,25,26,30,31</sup>

The randomized trial design was a strength for nine studies. <sup>16,17,24–26,30,32,33,35</sup> Eleven studies used a theoretical model to guide their research, which was considered a strength. <sup>13,15,17,21,22,25,27,30–33</sup> Only one study reported a low response rate (35%), <sup>15</sup> which may indicate questionable validity of the study results.

Misclassification of both the independent and outcome variables can be a concern for observational studies and may lead to information bias. Studies that relied exclusively on medical records for information on patient characteristics<sup>10–12,14,16,18–25,28–35</sup> may have misclassified these variables if they are not routinely available in medical records. Further, women who received follow-up care at other clinics may have been misidentified as nonadherent if self-reported follow-up was not available. Four studies obtained adherence information through self-report in addition to medical record abstraction; these studies both validated their outcomes using another source and were able to obtain complete documentation from other sites. 13,15,26,27 Another study<sup>17</sup> excluded women who reported followup at another clinic to avoid this bias.

Because lesion severity may directly impact the importance of and timeliness of adherence, we included assessment by lesion severity as a component of quality. Fourteen of 26 studies either conducted separate analysis by lesion severity or included only one type of lesion in their research. 10,11,15–21,25,26,28,29,32

As previously noted, having a range of adherence definitions makes comparisons across the studies challenging. In general, those studies with shorter time intervals for defining adherence may

be more prone to outcome misclassification. However, different types of noncompliance exist (e.g., delay in seeking care, nonparticipation in care, and cancellation of appointments), so all may be considered an appropriate measure.

Summary of reviewed research

Table 5 provides a summary of factors addressed by the literature included in this systematic review. Table 5 provides a breakdown of the associations by patient factors, psychosocial factors, and healthcare system factors. The strength of association corresponds to the range of point estimates (odds ratio [OR]/hazards ratio [HR]) for studies reporting a statistically significant association (Weak, OR/HR: 1.0-1.49 or 0.68-1.0; moderate, OR/HR: 1.5-3.0 or 0.33-0.67; strong, OR/HR: 3.0-10.0 or 0.10-0.32). Furthermore, Table 5 indicates the number of high-quality studies that contributed to the results.

#### **DISCUSSION**

Over the past 15 years, many factors have been hypothesized to affect adherence to follow-up procedures following an abnormal Pap test. In this discussion, we focus on modifiable risk factors for adherence at the patient, psychosocial, and healthcare system levels and address future directions for research.

## Patient factors

Among those modifiable factors associated with the patient, the majority of studies included in this review agreed that women with less severe lesions were less likely to be adherent to follow-up care. 10,11,14,16,18,20,25,26,28,29,32 Reasons for this association may include a belief of both women and clinicians that follow-up is less important for less severe Pap test results. Although this may in general be true, all women recommended for follow-up should receive follow-up care in a timely manner, as some less severe lesions may become more severe without follow-up. Potential interventions may include stressing the importance of follow-up regardless of lesion severity during patient-provider meetings and within educational materials addressing abnormal Pap

The Pap test can detect lesions that will never progress to cervical cancer; therefore, women

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Barriers	Number of studies that addressed factor	Number of studies that reported an association with factor	Strength of association <sup>a</sup>	Number of high-quality studies <sup>b</sup>
Patient factors Age	14 (10, 11, 14, 16–18, 20,	7 (16, 17, 20, 25–27, 34)	Weak-Moderate	8 (10, 11, 17, 18, 20,
Race African American	(10, 11, 16-18, 23.28, 30, 32.78	7 (10, 11, 17, 18, 25 )	Moderate-strong	(10, 11, 17, 18, 25, 26, 30, 31, 32)
Asian	7 7 7 21 21 24)	20, 32) 4 (12-16-17-18)	Moderate-strong	20, 30, 31, 32) 3 77 10 21)
Hispanic	(12, 10–10, 27, 34) 12 (16–18, 23–28, 30, 31, 34)	(12, 10, 17, 10) 2 (18, 25)	Moderate	(17, 18, 25, 26, 30, 31)
Language	3 (17. 29. 34)	No evidence	I	
Residence	(17, 23, 34) 2 (18, 20)	1 (10)	Moderate	1 (10)
Education	(16, 29) 5 77 30 31)	$\begin{pmatrix} 1 \\ 0 \end{pmatrix}$	No point estimate*	$\begin{pmatrix} 16 \\ 3 \\ 75 & 30 & 31 \end{pmatrix}$
Pregnancy	(24, 25, 21, 30, 31) 3 (17, 20, 28)	(2) 1 (20)	No point estimate*	(25, 35, 31) 2 (17, 20)
Gravity/parity	(17, 20, 20) 2 (14, 32)	$\begin{pmatrix} 20 \\ 1 \end{pmatrix}$	Moderate	$\begin{pmatrix} 1 \\ 1 \end{pmatrix}$
Tobacco	(14, 32) 2 (14, 33)	(32)	Moderate	$\begin{pmatrix} 32 \\ 1 \\ (32) \end{pmatrix}$
Insurance	(14, 32) $10$ $(14, 16, 17, 23)$	(32) 3 (25-29-34)	Moderate	(32) 2 (17-25-26)
Income/cost	(14, 10, 11, 25, 3 )	$\begin{pmatrix} 2 & 2 \\ 1 \end{pmatrix}$	No point estimate*	$\begin{pmatrix} 11, 29, 29 \end{pmatrix}$ $\begin{pmatrix} 1 \\ (31) \end{pmatrix}$
interventions	(15, 15, 31) 3 (31, 35, 36)	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	Moderate	(3)
Knowledge	(21, 23, 20) 2 (13, 31)	(23, 20) 2 (13, 31)	Weak-moderate	(21, 23, 20) 1 (31)
interventions	(15, 21) 7 (15, 17, 2/-26, 30, 32, 33)	7 7 37 37 33)	Moderate-strong	$\begin{array}{c} (31) \\ 5 \\ (17.25.36.30.32) \end{array}$
Lesion severity	(10, 11, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 23, (10, 14, 16–18, 20, 24, 16, 16, 16, 16, 16, 16, 16, 16, 16, 16	(10, 11, 14, 16, 18, 20, 25, 33)	Moderate-strng	(10, 11, 17, 18, 20, 32)

	1 (31)	(31) 2 (17, 30)	3 (25, 26, 30)	I	4 (17, 21, 26, 30)	I		(20)
	Weak	Moderate-strong	Moderate-strong	Strong	Moderate-strong	I	I	Moderate-strong
	1 (31)	(15, 17, 24, 30)	2 (13, 26)	3 (19, 27, 28)	5 (15–17, 26, 30)	No evidence	No evidence	2 (28)
	2 (27 31)	(15, 17, 24, 30)	6 (13, 14, 24–26, 30)	3 (19, 27, 28)	6 (15–17, 21, 26, 30)	3 (27. 28, 34)	1 (22)	(20, 28, 35)
Psychosocial factors	Psychological	interventions	Social support/marital status	Healthcare system ractors Communication/ management choice	Reminder protocols interventions	Clinician specialty	interventions	Facility characteristics

<sup>a</sup>Strength of association is defined by the range of point estimates (OR/HR) for statistically significant studies: weak, OR/HR: 1.0–1.49 or 0.68–1.0; moderate, OR/HR: 1.5–3.0 or 0.33–0.67; strong, OR/HR: 3.0–10.0 or 0.10–0.32.

<sup>b</sup>Quality of study defined by: power/sample size, use of theoretical model, study design, response rate, outcome misclassification, and separation of lesion severity in

analysis (Table 4). \* p = 0.001; no measure of strength or point estimate was reported in the study.

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who have an abnormal Pap test result of ASCUS are now routinely tested for human papillomavirus (HPV). Because most cervical cancer cases result from persistent HPV infection, proper education and counseling of the potential impact of a positive HPV result may motivate women to adhere to follow-up care in a timely manner.

Many women have noted lack of time, money, or insurance as barriers to receiving timely follow-up care.<sup>8,15</sup> Although the majority of studies found no association between economic factors and adherence, 14,17,21,23,26-28,31 transportation incentives and economic vouchers did significantly increase adherence.<sup>25,26</sup> Currently, the Breast and Cervical Cancer Treatment Act provides medical assistance through Medicaid to eligible women who were screened for and found to have breast or cervical cancer, including precancerous conditions. However, women who are ineligible for this service still may feel they cannot afford follow-up care; these women may benefit from targeted interventions to address economic barriers to follow-up care.

Misunderstanding of the purpose of a Pap test and the need for follow-up after an abnormal result were frequent barriers to care. <sup>13,15,24,31</sup> All interventions that addressed knowledge of the Pap test and cervical cancer significantly increased adherence rates. <sup>15,17,24–26,30,32,33</sup> The current knowledge gap can be addressed on a personal level by nurses, community health workers, and patient navigators tailoring informational needs to each woman. Furthermore, a need clearly exists for a comprehensive, easy to understand, and culturally acceptable brochure to aid in the education of women who have an abnormal Pap test.

### Psychosocial factors

Social factors, such as the ability to cope effectively with an abnormal result,<sup>30</sup> as well as other attitudinal beliefs that may be influenced by social support<sup>36</sup> or culture may be important and potentially modifiable risk factors for nonadherence. To illustrate, greater fatalism was associated with lower adherence rates in two studies reviewed;<sup>15,31</sup> further, fatalism appears to be a mediator in the association between race and adherence and, unlike race, is potentially modifiable.<sup>31</sup> The literature supports that the emotional reaction (e.g., fear, anxiety, and depression) to the news of an abnormal Pap test result may reduce

a woman's ability to return for follow-up care in a timely manner.<sup>8,15,17,24,30,31,37–39</sup> A small literature suggests that stressful events occurring in women's lives around the time of the abnormal Pap test may serve as competing life priorities, thereby reducing the likelihood of obtaining follow-up care.<sup>40–42</sup> Effective coping strategies to reduce psychological distress from an abnormal Pap result have been noted.<sup>13,43</sup> In order to reduce clinic no-show rates, we need a better understanding of the interactions among anxiety, distress, effective coping, and support as they affect adherence.

## Healthcare system characteristics

Although patients are ultimately responsible for following the recommendations of their clinicians, clear patient-provider or laboratory communications may have a positive impact on adherence. Enhanced communication between the patient and the provider in experimental studies included in this review resulted in increased adherence rates. 16,17,24,25,30,32,33 Interventions aimed at reducing this communication barrier included telephone reminder systems, counseling/educational sessions, and instructive and culturally relevant pamphlets. The success of these interventions is consistent with studies reviewed by Yabroff et al.4 and Abercrobmie.7 These interventions may differentially affect women across a range of socioeconomic levels, and were tailored to meet women's individual needs.

Little research has addressed individual characteristics of the provider in influencing the effectiveness of communication. Future directions for research could include elements of effective patient-provider communication. These may include observational studies with permissible videotaped interactions. The type of healthcare provider may vary (e.g., physician, nurse, health education counselor), but the ability of the provider to simply and effectively communicate medical information as well as personal concern for that patient would be an important contribution

## CONCLUSIONS

Inconsistent evidence for risk factors and barriers to receipt of follow-up care as well as extreme differences in reported adherence rates

across the 26 scholarly papers reviewed indicate that the influence of demographic, individual, and healthcare system level factors on adherence to abnormal Pap tests is undoubtedly complex. Women differ in their knowledge of cervical cancer screening, their attitudes toward preventive follow-up care, and their overall access to this care, including financial and transportation barriers. Similarly, healthcare providers differ in their attitudes and communication skills. The healthcare system may determine follow-up availability on site and extended clinic hours.

#### Future directions

A range of barriers for adherence to follow-up after an abnormal Pap test have been identified in the existing literature. Therefore, the most cost-effective strategy to overcome diverse barriers among at-risk populations will likely include tailored interventions through case management or patient navigation. Additionally, although many modalities of patient education are used (e.g., letter, pamphlets, videotape/DVD, phone calls, emails, websites), little research has addressed the content of the material in terms of the intended audience, the cultural competence for a range of audiences, or the accuracy in light of new HPV testing methods, screening, and follow-up options.

Successful interventions, if incorporated into everyday practice, may increase the short-term cost of healthcare services. A recent study by Wagner et al. 44 however, suggests that tailored counseling interventions may be more cost-effective than usual care among high-risk populations. 44 By reducing barriers to follow-up care for abnormal Pap tests, the financial cost of late-stage treatment for cervical cancer will decrease. Further, decreases in the adverse physical, psychological, and emotional effects of cervical cancer morbidity and mortality would be significant.

#### REFERENCES

- Schiffman MH, Brinton LA, Devesa SS, Fraumeni J, Joseph F. Cervical cancer. In: Schottenfeld D, Fraumeni J, Joseph F, eds. Cancer epidemiology and prevention. New York: Oxford University Press, 1996.
- 2. Cancer facts and figures 2006. Atlanta: American Cancer Society, 2006.
- 3. Hughes E, McCracken M, Roberts H, et al. Surveillance for certain health behaviors among states and selected local areas—Behavioral Risk Factor Surveil-

- lance System, United States, 2004. MMWR Surveill Summ 2006;55:1.
- Yabroff KR, Washington KS, Leader A, Neilson E, Mandelblatt JS. Is the promise of cancer-screening programs being compromised? Quality of follow-up care after abnormal screening results. Med Care Res Rev 2003;60:294.
- Leyden WA, Manos MM, Geiger AM, et al. Cervical cancer in women with comprehensive health care access: Attributable factors in the screening process. J Natl Cancer Inst 2005;97:675.
- 6. Bastani R, Yabroff KR, Myers RE, Glenn B. Interventions to improve follow-up of abnormal findings in cancer screening. Cancer 2004;101:1188.
- Abercrombie PD. Improving adherence to abnormal Pap smear follow-up. J Obstet Gynecol Neonat Nurs 2001;30:80.
- 8. Khanna N, Phillips MD. Adherence to care plan in women with abnormal Papanicolaou smears: A review of barriers and interventions. J Am Board Fam Pract 2001;14:123.
- McKee D Improving the follow-up of patients with abnormal Papanicolaou smear results. Arch Fam Med 1997;6:574.
- Benard VB, Lawson HW, Eheman CR, Anderson C, Helsel W. Adherence to guidelines for follow-up of low-grade cytologic abnormalities among medically underserved women. Obstet Gynecol 2005;105:1323.
- Cardin VA, Grimes RM, Jiang ZD, Pomeroy N, Harrell L, Cano P. Low-income minority women at risk for cervical cancer: A process to improve adherence to follow-up recommendations. Public Health Rep 2001;116:608.
- Carey P, Gjerdingen DK. Follow-up of abnormal Papanicolaou smears among women of different races. J Fam Pract 1993;37:583.
- Crane LA. Social support and adherence behavior among women with abnormal Pap smears. J Cancer Educ 1996;11:164.
- Eger RR, Peipert JF. Risk factors for noncompliance in a colposcopy clinic. J Reprod Med 1996;41:671.
- 15. Ell K, Vourlekis B, Muderspach L, et al. Abnormal cervical screen follow-up among low-income Latinas: Project safe. J Womens Health Gend Based Med 2002;11:639.
- Engelstad LP, Stewart SL, Nguyen BH, et al. Abnormal Pap smear follow-up in a high-risk population. Cancer Epidemiol Biomarkers Prev 2001;10:1015.
- 17. Engelstad LP, Stewart SL, Ostero-Sabogal R, Leung MS, Davis PI, Pasick RJ. The effectiveness of a community outreach intervention to improve follow-up among underserved women at highest risk for cervical cancer. Prev Med 2005;41:741.
- Fox P, Amsberger P, Zhang X. An examination of differential follow-up rates in cervical cancer screening. J Community Health 1997;22:199.
- Hartz LE, Fenaughty AM. Management choice and adherence to follow-up after colposcopy in women with cervical intraepithelial neoplasia 1. Obstet Gynecol 2001;98:674.

20. Jones BA, Novis DA. Follow-up of abnormal gynecologic cytology. Arch Pathol Lab Med 2000;124:665.

- 21. Kaplan CP, Bastani R, Belin TR, Marcus A, Nasseri K, Hu MY. Improving follow-up after an abnormal Pap smear: Results from a quasi-experimental intervention study. J Womens Health Gend Based Med 2000:9:779.
- 22. Lacey L, Whitfield J, DeWhite W, et al. Referral adherence in an inner city breast and cervical cancer screening program. Cancer 1993;72:950.
- Lavin C, Goodman E, Perlman S, Kelly LS, Emans SJ. Follow-up of abnormal papanicolaou smears in a hospital-based adolescent clinic. J Pediatr Adolesc Gynecol 1997;10:141.
- Lerman C, Hanjani P, Caputo C, et al. Telephone counseling improves adherence to colposcopy among lower-income minority women. J Clin Oncol 1992;10: 330.
- 25. Marcus AC, Crane LA, Kaplan CP, et al. Improving adherence to screening follow-up among women with abnormal Pap smears: Results from a large clinicbased trial of three intervention strategies. Med Care 1992;30:216.
- 26. Marcus AC, Kaplan CP, Crane LA, et al. Reducing loss-to-follow-up among women with abnormal Pap smears. Results from a randomized trial testing an intensive follow-up protocol and economic incentives. Med Care 1998;36:397.
- McKee MD, Lurio J, Marantz P, Burton W, Mulvihill M. Barriers to follow-up of abnormal Papanicolaou smears in an urban community health center. Arch Fam Med 1999;8:129.
- 28. McKee MD, Schechter C, Burton W, Mulvihill M. Predictors of follow-up of atypical and ASCUS Pap test results in a high-risk population. J Fam Pract 2001;50:609.
- Melnikow J, Chan BK, Stewart GK. Do follow-up recommendations for abnormal Papanicolaou smears influence patient adherence? Arch Fam Med 1999;8:510.
- 30. Miller SM, Siejak KK, Schroeder CM, Lerman C, Hernandez E, Helm CW. Enhancing adherence following abnormal Pap smears among low-income minority women: A preventive telephone counseling strategy. J Natl Cancer Inst 1997;89:703.
- 31. Nelson K, Geiger AM, Mangione CM. Effect of health beliefs on delays in care for abnormal cervical cytology in a multiethnic population. J Gen Intern Med 2002;17:709.
- 32. Paskett ED, Phillips KC, Miller ME. Improving compliance among women with abnormal Papanicolaou smears. Obstet Gynecol 1995;86:353.

- 33. Paskett ED, White E, Carter WB, Chu J. Improving follow-up after an abnormal Pap smear: A randomized controlled trial. Prev Med 1990;19:630.
- 34. Peterson NB, Han J, Freund KM. Inadequate followup for abnormal Pap smears in an urban population. J Natl Med Assoc 2003;95:825.
- Takacs P, Chakhtoura N, DeSantis T. Video colposcopy improves adherence to follow-up compared to regular colposcopy: A randomized trial. Arch Gynecol Obstet 2004;270:182.
- 36. Trimble EL, Harlan LC, Clegg LX. Untreated cervical cancer in the United States. Gynecol Oncol 2005;96: 271.
- Bell S, Porter M, Kitchener H, Fraser C, Fisher P, Mann E. Psychological response to cervical screening. Prev Med 1995;24:610.
- 38. Fylan F. Screening for cervical cancer: A review of women's attitudes, knowledge, and behavior. Br J Gen Pract 1998;48:1509.
- 39. Lerman C, Miller SM, Scarborough R, Hanjani P, Nolte S, Smith D. Adverse psychologic consequences of cytologic cervical screening. Am J Obstet Gynecol 1991;165:658.
- Breitkopf CR, Catero J, Jaccard J, Berenson AB. Psychological and sociocultural perspectives on followup of abnormal Papanicolaou results. Obstet Gynecol 2004;104:1347.
- 41. Coker AL, Bond SM, Brandt HM. Reasons women discontinue paid follow-up care for pre-invasive neoplasia. Am J Epidemiol 2002;155(11)Suppl:S3.
- Lovejoy NC, Roche N, McLean D. Life stress and risk of precancerous cervical lesions: A pretest directed by the life stress model. Oncol Nurs Forum 1997;24:63.
- Lauver DR, Baggot A, Kruse K. Women's experiences in coping with abnormal Papanicoloau results and follow-up colposcopy. J Obstet Gynecol Neonat Nurs 1999;28:283.
- 44. Wagner TH, Engelstad LP, McPhee SJ, Pasick RJ. The cost-effectiveness of an outreach intervention for women with abnormal pap smears: VA Palo Alto and Stanford University, 2005.

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- 2. Sanja Percac-Lima, Leslie S. Aldrich, Gloria B. Gamba, Adriana M. Bearse, Steven J. Atlas. 2010. Barriers to Follow-Up of an Abnormal Pap Smear in Latina Women Referred for Colposcopy. *Journal of General Internal Medicine* 25:11, 1198-1204. [CrossRef]
- 3. Monique A. Tello, Mollie Jenckes, Jennifer Gaver, Jean R. Anderson, Richard D. Moore, Geetanjali Chander. 2010. Barriers to Recommended Gynecologic Care in an Urban United States HIV ClinicBarriers to Recommended Gynecologic Care in an Urban United States HIV Clinic. Journal of Women's Health 19:8, 1511-1518. [Abstract] [Full Text] [PDF] [PDF Plus]
- 4. J. Zapka, S. H. Taplin, R. Anhang Price, C. Cranos, R. Yabroff. 2010. Factors in Quality Care--The Case of Follow-Up to Abnormal Cancer Screening Tests--Problems in the Steps and Interfaces of Care. JNCI Monographs 2010:40, 58-71. [CrossRef]
- 5. Tzy-Mey Kuo, Vicki B. Benard, Nancy D. Berkman, Carolyn K. Martin, Lisa C. Richardson. 2010. Timing of Colposcopy After Cervical Cytologic Abnormalities. *Obstetrics & Gynecology* 115:3, 629-636. [CrossRef]
- 6. Tracy A. Battaglia, M. Christina Santana, Sharon Bak, Manjusha Gokhale, Timothy L. Lash, Arlene S. Ash, Richard Kalish, Stephen Tringale, James O. Taylor, Karen M. Freund. 2010. Predictors of timely follow-up after abnormal cancer screening among women seeking care at urban community health centers. *Cancer* 116:4, 913-921. [CrossRef]
- 7. Jessica Warman. 2010. Cervical Cancer Screening in Young Women: Saving Lives With Prevention and Detection. *Oncology Nursing Forum* 37:1, 33-38. [CrossRef]
- 8. Su-Ying Fang, Bih-Ching Shu. 2009. Adherence Characteristics After Abnormal Screening Results Between Mammogram and Papanicolaou Test Groups. *Cancer Nursing* **32**:6, 437-445. [CrossRef]
- 9. Meg Watson, Mona Saraiya, Vicki Benard, Steven S. Coughlin, Lisa Flowers, Vilma Cokkinides, Molly Schwenn, Youjie Huang, Anna Giuliano. 2008. Burden of cervical cancer in the United States, 1998-2003. *Cancer* 113:S10, 2855-2864. [CrossRef]
- Vicki B. Benard, William Howe, Mona Saraiya, William Helsel, Herschel W. Lawson. 2008. Assessment of Follow-Up for Low-Grade Cytological Abnormalities in the National Breast and Cervical Cancer Early Detection Program, 2000-2005. *Journal* of Lower Genital Tract Disease 12:4, 300-306. [CrossRef]
- 11. Carlos E. Pineda, J. Michael Berry, Naomi Jay, Joel M. Palefsky, Mark L. Welton. 2008. High-Resolution Anoscopy Targeted Surgical Destruction of Anal High-Grade Squamous Intraepithelial Lesions: A Ten-Year Experience. *Diseases of the Colon & Rectum* 51:6, 829-837. [CrossRef]
- Ann Scheck McAlearney, Katherine W. Reeves, Stephanie L. Dickinson, Kimberly M. Kelly, Cathy Tatum, Mira L. Katz, Electra D. Paskett. 2008. Racial differences in colorectal cancer screening practices and knowledge within a low-income population. *Cancer* 112:2, 391-398. [CrossRef]