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Research Article

Barriers and Facilitators to Follow-up Adherence after an Abnormal Pap Smear: Evidence and Implications for Practice

Stacie Sweet*

Ohio University Zanesville, Associate Professor of Nursing, Ohio, USA

***Corresponding author**: Stacie Sweet, Ohio University Zanesville, Associate Professor of Nursing, 1425 Newark Road, Zanesville, Ohio 43701, USA. Tel: +17405881497; E-Mail: sweets@ohio.edu

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Abstract

The purpose of this Evidence-Based Practice (EBP) project was to ascertain common barriers and facilitators that influence patient's ability to keep scheduled follow-up appointments after an abnormal Pap smear and suggest possible interventions to increase follow-up adherence. Melnyk and Fineout-Overholt's (2011) evidence-based practice guidelines were utilized to guide the research process. A review of the literature as well as a small study contribute to the body of evidence which can be utilized. The setting of interest is a federally-funded, rural women's health clinic, in southeastern Ohio. Participants included 49 female participants aged 18-66 years and 7 clinicians providing direct care to these patients. Most of the results of this project are consistent with the literature. Women report that transportation, financial barriers, and fear may impede their ability to return for follow-up appointments while health care providers report transportation, health literacy and financial burdens may decrease adherence. Utilization of the evidence can help patients and staff in mitigating barriers and facilitating interventions to improve patient adherence to recommendations.

Keywords: Attitudes; Health Knowledge; Health Promotion; Health Services Accessibility; Practice; Patient Compliance; Papanicolaou Smear; Papanicolaou Test; Secondary Prevention; Sexually Transmitted Diseases; Vaginal Smears; Women's Health

Introduction and Background

Cervical cancer is one of the most preventable cancers because of its slow progression, cytologically identifiable precursors and effective treatments. Yet, it remains the third most common gynecological malignancy diagnosed and the fourth leading cause of cancer deaths among women worldwide [1]. According to the Centers for Disease Control and Prevention, the most recent statistics indicate that 11,955 women were diagnosed with cervical cancer in 2013 and 4,217 died. When diagnosed early, the likelihood of survival is close to 100% [2]. A key reason for the high number of deaths caused by this preventable cancer is failure to obtain follow-up care after an abnormal screening with the Pap smear. The rates of loss to follow-up for abnormal Pap smears have been found to range from 30% to 50% [3]. The purpose of this EBP project was to ascertain the best evidence on ways to increase adherence to follow-up care recommendations and suggest possible interventions for a Federally Qualified Health Center (FQHC) in Southeastern Ohio.

Cultivating a Spirit of Inquiry

Within southeastern Ohio there is a federally qualified health center whose mission is to provide high quality, affordable health care services to medically underserved populations regardless of their ability to pay. Loss to follow-up care has been recognized as a potentially life-threatening consequence for women within this health center. Despite the fact that there are some interventions in place such as an automated telephone reminder system and in some cases transportation vouchers, the number of patients with abnormal Pap smears who do not follow-up in a timely manner or do not follow-up at all remains high. This prompted the author to want to obtain evidence that would assist in determining what interventions would help these women keep their follow-up appointments and could be used to develop a plan for the health center.

PICOT Question

A PICOT question (P=Patient Population, I=Issue of Interest, C= Comparison Group, O=Outcome, and T=Timing) was developed to guide the literature search and the development of the patient and staff questionnaires. For this project, there was not a comparison group. The PICOT question was "In women receiving gynecological care (P), what interventions (I) will reduce barriers and facilitate adherence to follow-up (O) after abnormal Cervical Cytology (T)?"

Search for the Best Evidence

It is important to focus on barriers that are amenable to intervention; therefore, a literature search on the best evidence for intervention was conducted. Using the databases PubMed, CINAHL and Cochrane, a search for articles published from 1990-2017 was conducted. The keywords used from the PICOT question in the search process were: barriers facilitators, adherence, Pap smear and follow-up. The search was limited to the English language. This search yielded a total of 25 articles adding to the body of evidence related to barriers and facilitators to adherence to follow recommendations for abnormal Pap smears. The search methods were validated by a Health Sciences Librarian who has expertise in EBP.

Presentation and Critical Appraisal of the Evidence

The 25 articles found were examined for validity (whether or not the results of the study were obtained from sound scientific methods), reliability (whether or not the effects from the study have sufficient influence on practice) and applicability (whether or not the effects of the study are appropriate for a particular patient situation). Of the articles that focused on intervention studies, five were systematic reviews or meta-analysis. The systematic reviews yielded results of studies related to barriers to follow-up care and improving adherence to follow-up care after an abnormal Pap smear during a span from 1966-2014. There are multiple factors associated with adherence to follow-up recommendations, including both demographic and psychosocial patient factors as well as healthcare system influences [2]. Demographic barriers include younger or older age, nonwhite race, and lower educational level. Financial barriers include lack of insurance or ability to pay for care. Psychological issue includes fear and beliefs about health and cancer. Accessibility to care is demonstrated by individuals not having the time to attend multiple appointments, transportation issues and lack of childcare. Other barriers found to affect adherence include forgetting the follow-up appointment being asymptomatic and not having follow-up recommendations from health care providers. In some instances, there are administrative problems such as incorrect patient addresses and phone numbers making it difficult contact patients. Five systematic reviews indicate that effective strategies to improve patient adherence to follow-up recommendations include: (a) structured educational/counseling phone calls, (b) transportation and financial incentives, (c) office-based reminder calls and letters, (d) educational brochures and handouts regarding abnormal Pap smears, (e) slide-taped presentations, (f) and case management tracking Seven randomized control studies and one quasi-experimental intervention study was reviewed. One study was conducted using patients from 12 different primary health care clinics. Seven studies were conducted in various units of a hospital or medical center, all of which were located in the United States. The majority of the intervention studies used sample populations predominantly including minority women of African American (ranging from 13%-86% of the total number of participants) or Hispanic descent (ranging from 17% to 80.6% of the total number of participants). Those that were Caucasian in the studies ranged from 6%-24% of the total number of participants representing a much smaller portion of the total. The larger proportion of participants was uninsured or relied on public assistance for medical expenses. The participants were relatively young in age with most under age 35 years. One intervention study used a sample of predominately white women with an average age of 31 years, well educated, and in the middle and upper social classes. Sample sizes for all the intervention studies ranged from 108 to 4,488 participants. Intervention study times ranged from 6 months to 3 ½ years following abnormal Pap smears. Results from these studies revealed that single or a combination of interventions is effective in improving patient adherence rates. Two studies found that telephone counseling is more effective than standard care for improving adherence to follow-up [4,5]. Two studies describe the effectiveness of a computerized tracking system [6,7]. In a study involving a combination of interventions including a personalized follow-up letter and educational pamphlet and a slide taped program describing Pap smears and the importance of follow-up compared to transportation incentives alone, transportation incentives were found to be the most effective at improving adherence rates [8]. A second study that involved transportation incentives along with two other interventions found similar rates of receipt of follow-up care but did not find strong evidence for intervention effects [9]. Interventions supported in other studies which have been shown to improve adherence to follow-up care are: (a) educational pamphlets, (b) notification letters, (c) financial incentives, (d) telephone reminders, (e) and slide-taped education. Young Suk & Jeong Sook, 2014 found the main reason that patients follow up for abnormal pap smear is receiving recommendations from health care providers. They also found that almost half the patients in their study returned for follow up when they had doubts about the progress of cervical cancer. Other factors included symptoms of disease such as vaginal bleeding and discharge, recommendations from female friends and family and discounted expenses. Limitations of the studies include a lack of consensus on the definition of "Adherence". Some studies refer to adherence as a patient who

completed all recommended follow-up appointments. Others defined adherence as a patient that presented for at least one follow-up appointment. Another limitation to the studies is that all but one of the studies used a sample of predominately minority women of African American or Asian descent which may limit the generalizability to white women. Although each intervention study had limitations, all documented some improvement in adherence to follow-up with intervention. In addition, each study provides and supports the development of future interventions.

Qualitative Studies

The purpose of the single qualitative meta-analysis was to determine the effectiveness of interventions designed to improve follow-up after abnormal Pap smear. The criteria for the analysis included: randomized or concurrently controlled study design, defined outcomes, and data available for abstraction. Interventions were classified as behavioral, cognitive, sociologic, or combined strategies. Twenty-two interventions in ten studies were reviewed. The most effective cognitive intervention included telephone counseling, improving adherence by 24-31%. Behavioral interventions such as patient reminders increase adherence by 18%. Video-taped peer discussions were found to be the only sociologic intervention and were not found to be associated with an improvement in follow-up. There were eight distinct interventions in three studies that used a combination of strategies. Most of the behavioral and cognitive combinations yielded an improvement in compliance by 7-13%. Varying effectiveness was found in the behavioral and sociologic or the behavioral, sociologic and cognitive combinations. Limitations of the studies included a varying definition of abnormal Pap smear, follow-up outcome measurement and time frame used to assess follow-up. Variability in the patient populations studied could also have an effect on the interpretation of the results. The samples of the remaining 11 studies were varied. The sample sizes ranged from 40-1216 participants. In the studies, most participants were under age 35, had completed high school, and were uninsured or covered by public assistance. The majority of studies obtained information from women of racial or ethnic minorities. The literature indicates that facilitators to follow-up care include reminders, transportation and financial incentives, and educational materials help to facilitate adherence to follow-up recommendations.

Integration of Evidence

It is unknown whether women at a federally qualified health center have similar barriers and facilitators to adherence to follow-up recommendations after an abnormal Pap smear as women studied in the literature. To assess this, patient data was obtained from women in the health center and compared to the data found in the literature. To add to the evidence, data was also obtained from clinicians who provide care to the women at the health center.

Project Procedure

Patients were conveniently chosen based on their presence at the health center for an appointment in the gynecological service line. The investigator felt that trying to obtain information strictly from patients who did not ever return for a follow-up appointment due to an abnormal Pap smear would be difficult. This was concluded because many patients do not have current contact information available and have not been seen at the health center for more than a year. However, within the data collected, it is likely that there would be some patients that have had an abnormal Pap smear in the past but did not follow-up in a timely manner or had missed

one or more scheduled appointments prior to being seen for follow-up care. It is essential to identify what barriers prohibited them from following the recommendations provided by their health care provider. For the patients that have not missed any appointments, their perspective on facilitators to follow-up is important. Since the health center where the data was collected is not governed by an Institutional Review Board (IRB), approval was sought and obtained from The Ohio State University's Institutional Review Board. Since the health center does not have its own review board, appropriate approvals from administration were obtained. After IRB approval, packets were distributed to patients presenting to the gynecological service line who met inclusion criteria. Inclusion criteria included: the participant was at least 18 years of age, was a patient in the gynecological service line at the FQHC, and was able to read and write. Exclusion criteria included the patient who was under age 18 years, failed to consent, and/or could not read and write. The packets were distributed by trained staff members. The packet consisted of a copy of the informed consent accompanied with a cover letter explaining the purpose of the questionnaire, the questionnaire and an envelope. The participant completed the questionnaire in the exam room while waiting to be seen by the provider. After completing the questionnaire, it was placed into the enclosed envelope and sealed by the participant. Following the participant's office visit, the sealed envelope was collected by a staff member and returned to the investigator. Staff members providing Pap smears to patients at the health center were provided with a packet. Their packet consisted of a cover letter explaining the purpose of the questionnaire, an informed consent, the questionnaire and an envelope marked with staff. Staff who consented to participate completed the questionnaire and then placed into the envelope. They were instructed to seal the envelope and return it to the investigator.

Questionnaires

The patient questionnaires were formatted in a check box format for quick, easy responses as well as open-ended questions that allowed the participant to provide more expressive answers.

The patient questionnaire included demographic information including age, race, education level, income, work status, marital status, number of children and insurance coverage. There were questions which helped determine the patient's history of abnormal Pap smears, education received regarding their abnormal Pap and information about scheduling. Staff questionnaires were used to obtain data about their perceptions of patient's responses to follow-up care, perceptions of patient knowledge of the Pap smear results, perceptions of the patient's own health and perception of the patient's ease of accessibility to care. These were written as open-ended questions. There was one check-box question which asked for the staff member to identify their role as a staff member.

Data Analysis

Descriptive data analysis was used to analyze closed-ended questions. Open ended responses were analyzed using McLaughlin and Marascuilo's (1990) three-phase content analysis technique. The first phase of the content analysis was to identify individual units of analysis, (i.e. a thought or a theme that appeared in the response). Each thought or theme was bracketed on copies of raw, de-identified data, independently by two trained coders. Units of analysis were compared between members, and an Interrater Reliability (IRR) percent agreement was calculated using the following formula: IRR = (NA –N8)/Total where NA = number of agreements, N8 = number of disagreements, and the Total = the total number of bracketed thoughts/themes. The investigators determined that an adequate IRR is 0.90 agreement. If there was disagreement on any unit, it was discussed until a consensus was reached. All units coded were > 98% prior to discussion. The second phase of the content analysis required a coder to create mutually exclusive and exhaustive categories that incorporated all of the thoughts or themes (i.e. units), then develop names and definitions for each category. A priori level of 90% agreement was determined as acceptable for interrater reliability. For the third phase, all units were > 90% prior to discussion. Frequencies and percentages for each category were calculated.

Results

Results of Patient Surveys

Fifty women completed the questionnaires. Demographic information for the patients is included in (Table 1). The women ranged in age from 18 to 66 years-old (M = 35; SD = 11.54). One participant was excluded because she did not meet inclusion criteria, making the final total 49. All participants reported that their primary language was English. The majority was Caucasian (86.7%), single/divorced /separated (63.3%), insured by public assistance or without insurance (83.4%), and had completed at least nine to twelve years of education (98 %). Seventy-one percent of the participants reported that they presented for a Pap smear. Of the participants, approximately 43% percent indicated that they have had an abnormal Pap smear in the past and more than half (60.2%) of these patients did not follow up according to the recommendations of their health care provider. Patient reasons that prevent them from returning for follow-up visits included transportation issues/distance to travel (15.0%), negative experiences (13.8%), financial barriers (13.8%), and fear (7.5%) (see Table 2). Patients reported that having a positive experience (23.1%), motivation by health (i.e. patient is not sick, is in good health) (13.5%), financial assistance (11.5%), and flexible scheduling (11.5%) would help them keep their follow-up appointments (see Table 3).

	n	Minimum	Maximum	Mean	Std. Deviation
Age in years	49	18	66	35.6	11.54439
Hours worked outside the home	47	0	40	15.9	16.93187
Number of children	49	0	5	1.8	1.42887

	n	%
Race/ethnicity		
White	39	79.6
African American More than 1 race	5	10.2
Relationship status	1	2
Single Married Divorced Separated		
Living together Work outside the home	17	34.7
Yes No	14	28.6
Income	10	20.4
$0-5,000	4	8.2
$5,001-10,000	4	8.2
$10,001-20,000		
$20,001-30,000	25	51
$30,001-40,000	23	46.9
$40,001-50,000		
Over $50,000	10	20.4
	5	10.2
Insurance	12	24.5
Private Medicaid Medicare	4	8.2
No Insurance	3	6.1
	2	4.1
	1	2
	7	14.3
	20	40.8
	2	4.1
	18	36.7

Table 1: Characteristics of Patient Sample.

Category	n	%
Positive experience Motivated by health Financial assistance Flexible scheduling Keeps Appointments Reminders Transportation assistance	12	23.1
Not amendable to assistance Appointment time/ length Assistance with fear Encodable response	7	13.5
	6	11.5
	6	11.5
	6	11.5
	5	9.6
	4	7.7
	2	3.8
	1	1.9
	1	1.9
	1	1.9

Table 3: Patient Responses to Things that Help Them Keep Follow-up Appointments.

Results of Staff Surveys

There was a total of seven staff members that completed questionnaires; three physicians, three nurse practitioners/physician assistants, and one social worker. Staff results (see Table 4) revealed that 26.1% believed that transportation was a reason that prevents patients from returning for follow-up appointments. The next most frequently reported reason was health literacy issues (17.4%) and the third most commonly reported reason was financial barriers. The three most commonly reported responses from staff for things that could help patients keep their appointments were transportation assistance (25.0%), reminders (20.0%), and improving health literacy (15.0%) (see Table 5).

Category	n	%
Transportation Health literacy issues Financial Childcare	6	26.1
	4	17.4
System navigation issues	3	13
Unwillingness or lack of motivation to adhere Illness	2	8.7
Weather	2	8.7
Resolution of the problem Forgot appointment	2	8.7
	1	4.3
	1	4.3
	1	4.3
	1	4.3

Table 4: Staff Responses to Things that Prevent Patients from Returning for Follow-up.

Category	n	%
Transportation assistance Reminders	5	25
Improving health literacy Improving system knowledge Provide childcare	4	20
Financial assistance Incentives for visits Navigation Services Flexible scheduling	3	15
	2	10
	2	10
	1	5
	1	5
	1	5
	1	5

Table 5: Staff Responses to Things that Help Patients Keep their Appointments.

Discussion

The women from the FQHC who participated in this EBP project had similar demographic characteristics as those in the literature [2,4,6,8]. These similarities make the information obtained from the literature more appropriate for developing interventions to assist women at the FQHC. The average age of the participants was mid-thirties. Most of the women had completed high school and were unemployed or employed part-time. The majority of the participants were uninsured or insured by public assistance. Many were single, divorced or separated and had at least one child. There were also some differences between the sample of women at the FQHC and the published literature with the biggest difference being race. Most of the evidence from the literature is based on samples of predominately African American or Hispanic women [4,6,7]. The majority of the women from the FQHC were Caucasian. Commonly reported FQHC patient responses that prevented them from returning for follow-up care were transportation, finances and fear. Similar barriers were found in the literature. Patients at the FQHC frequently reported that having a negative experience, defined as a bad or negative experience with staff, less than optimal condition of the environment (i.e. cleanliness) or lack of tending from care providers were all important reasons for not returning for follow up care. This is unique to this sample and was not found to be a dominant barrier in the literature. It is interesting that the study revealed that only two participants reported that forgetting the appointment was a reason for not returning for follow-up but the literature supports that reminders significantly increased the rate of follow-up care. Patients at the FQHC believe that one of the most important facilitators includes having a positive experience. Having a good experience was described as being treated with respect, having friendly staff, the facility being clean and being seen by the provider on time. Other reported facilitators were financial assistance, flexible scheduling and reminders. They also reported that returning for appointments is facilitated by being in good health, meaning that they are more likely to return if they are not sick.

Recommendations for a Practice Change

The information obtained from this EBP project will be valuable

in tailoring, client- centered approaches to follow-up care based on integrating best evidence with professional judgment and expertise and with client preferences. Given the evidence, women at the FQHC frequently reported that transportation and financial barriers, fear, and negative experiences may impede their ability to return for follow-up appointments. A combination of interventions could be incorporated into the care of these patients utilizing information obtained from the literature and feedback provided from the patients and staff at the FQHC.

An In-service Conducted by the Director of the Quality Committee

Women at the FQHC reported that a positive experience would help them keep their scheduled appointments. An in-service conducted by the Director of the Quality Committee could be given to all employees including ancillary staff regarding the professional treatment and respect for patients and things that can be done to ensure that patients have a positive experience from the time of entry to time of discharge. Included would also be information regarding professionalism for those who talk to patients on the phone.

Centralized Computerized Tracking System

Centralized computerized tracking systems could be utilized. The FQHC has recently changed from paper charting to an electronic medical record which could possibly meet the needs of a centralized computerized tracking system. A follow-up coordinator who is a registered nurse would be responsible for using the tracking system to monitor the patients who need follow-up care. Utilizing this computerized tracking system would prompt the registered nurse to contact the patient via the phone for a one-on-one educational/counseling session.

Telephone Counseling/Education Session

Patients reported that fear may impede follow-up care. Fear may be caused from misperceptions about what the abnormal Pap result means, that they may be treated differently because a high percentage of abnormal Pap smear results are caused by the human papilloma virus which is a sexually transmitted disease, and fear of what the follow-up procedures entail. The feelings of fear may be exacerbated when adequate education is not provided to the patient at the time they are notified of their abnormal Pap smear result. An automated reminder phone call system is currently in place at the FQHC but a one-on-one education/counseling session conducted by a registered nurse could also be used. Evidence shows that interactive phone counseling sessions are instrumental in helping patients keep their appointments [5,10,11]. This allows the nurse making the calls to assess the educational and emotional needs of the patients and to allow the patient to ask questions about the follow-up care. It also provides an opportunity for rescheduling the appointment if necessary that is convenient for the patient and also verifying the patient's current address and updating their contact information in the system.

Educational/Reminder Letter and Transportation/Financial Incentives

Following the telephone counseling session, an informational/reminder letter would be mailed to the patient explaining the importance of follow-up and reminding them of the appointment date and time. As determined during the counseling session, if transportation or financial barriers were identified as reasons for not returning, a transportation voucher (gas voucher or bus/cab pass) would be sent with the letter. The possibility of providing a financial voucher to those who are without insurance could be discussed with administration. The voucher would offset the required co-pay and decrease the out-of-pocket expense to the patient.

Next Steps

Based on current literature and results of this small study directly related to the patient population within the FQHC, implementation of the discussed interventions and tracking of follow-up adherence rates could be implemented as the next step to improving patient adherence to abnormal pap smear follow-up. This EBP project used data collected from a relatively small sample of women and staff members and would provide data that is more generalizable if a larger sample were used. In the future, the project could be replicated with a larger sample of women and staff at other similar health centers.

Conclusion

The death rate from cervical cancer should not be as high as it is, however, in order to decrease these numbers, we must utilize the evidence to decrease barriers and increase facilitators to follow-up care after an abnormal Pap smear result. This EBP project adds to the body of evidence by providing additional identified barriers and facilitators that are not currently highlighted in the literature. Determination of the most frequent barriers to patient follow-up within an agency incorporated with evidence from the literature can help with development, implementation and evaluation of interventions. Incorporation of the evidence into clinical practice can lead to better patient outcomes.

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