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Faith Moves Mountains: An Appalachian Cervical Cancer Prevention Program

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Abstract

Objective—To provide a conceptual description of Faith Moves Mountains (FMM), an intervention designed to reduce the disproportionate burden of cervical cancer among Appalachian women.

Methods—FMM, a community-based participatory research program designed and implemented in collaboration with churches in rural, southeastern Kentucky, aims to increase cervical cancer screening (Pap tests) through a multiphase process of educational programming and lay health counseling.

Results—We provide a conceptual overview to key elements of the intervention, including programmatic development, theoretical basis, intervention approach and implementation, and evaluation procedures.

Conclusions—After numerous modifications, FMM has recruited and retained over 400 women, 30 churches, and has become a change agent in the community.

Keywords

cervical cancer; rural; interventions; Appalachia

In this article, we present a conceptual description of one of the first faith-placed intervention trials in Appalachia, a region with well-documented health disparities. The intention of the article is to provide readers with an in-depth understanding of the contextual, theoretical, and methodological components of the project, beyond the capacities of a standard data-driven paper. Conceptual descriptions of interventions have a time-honored tradition within behavioral science/public health as a means of providing in-depth explanations on the process, conduct, and progress of complex interventions.¹⁻³

Over the past decade, approximately 13,000 new cases of invasive cervical cancer have been diagnosed in the United States each year, with 4600 deaths resulting annually.⁴ These numbers represent a 75% reduction from the previous 5 decades, generally attributable to the proliferation of Pap smear screening, increased availability of diagnostic testing, and improvements in treatment.⁵ Pap test screening reduces the likelihood of invasive cervical cancer onset by 90% for up to 3 years.⁶ Indeed, 50 to 70% of new cervical cancer cases occur in seldom or never screened women. The current US Preventive Services Task Force recommends the following regarding Pap test screening: initiate Pap testing within 3 years of onset of sexual activity or by age 21, whichever comes first; obtain Pap test every 3 years; discontinue Pap test for women age 65 and older who have had negative tests and are not otherwise at high risk for cervical cancer and for women who have had hysterectomies for benign reasons.⁷

The high level of efficacy of cervical cancer screening has led the guiding public health document Healthy People 2010 to set a goal of 97% 3-year screening rate for women age 18 +.⁸ Although this goal remains elusive, rates of screening have increased over the past several decades. In 1970, 68% of women indicated that they had a recent (≤ 3 years) Pap smear. By 1997, this percentage had increased to nearly 80%.⁹ Unfortunately, these high rates of Pap tests have not been consistent across all regions of the United States, and several areas, including Appalachian Kentucky, have persistent patterns of low participation in screening.

Appalachia and Cervical Cancer Disparities

The Appalachian region includes 410 counties in 13 states and has a population of over 22 million people, or 8.3% of the total US population.¹⁰ Appalachia is well known as a region of beauty, community connectedness, poverty, and substandard health.¹¹ Although poverty rates have been cut in half since 1960, significant socioeconomic and health disparities persist.¹² High poverty levels in conjunction with other contextual challenges strongly contribute to the excess cervical cancer burden experienced by Appalachian women and their families.¹³ As demonstrated in Figure 1, Surveillance, Epidemiology, and End Results (SEER) data from Appalachia reveal that invasive cervical cancer incidence rates are 40% higher than the national average.¹⁴

To address this cancer burden in Appalachia, Faith Moves Mountains targeted women aged 40-64, years when many women stop having regular Pap tests just as cervical cancer rates increase, as shown in Table 1.

Determinants of Pap Test Receipt

Comprehensive frameworks that examine the determinants of cancer prevalence and mortality focus on characteristics of (1) the individual, (2) the health care provider and the medical system, and (3) the environmental or community context.¹⁵ Several reasons specific to the individual have been suggested for this elevated rate of cervical cancer and mortality, including the older age of women in Appalachia and the lack of resources pervasive in the region. Due to a general trend in population aging and outmigration of younger people, Appalachia's population is older than national figures,¹⁰ a concern because older age is associated with inadequate cervical cancer screening and higher mortality.¹⁶ Middle-aged and older women may not receive Pap tests due to a lack of regular reproductive health care, competing demands, and uncertainty about screening recommendations, factors described by women in our formative research.¹⁷

In addition, Appalachian residents are more likely to experience individual and community challenges, like poverty, lack of transportation, and low rates of adequate health insurance, that increase the risk of inadequate screening and cervical cancer.¹⁸ Health care professional

shortages endemic in Appalachia make it more difficult for lower income women to have access to preventive health services.¹¹ Recently, attention has been turned to understanding the linkage between elevated cervical cancer rates and HPV in the Appalachian context although, to our knowledge, the prevalence of HPV in Appalachia is unknown.

Faith Moves Mountains (FMM) focused on the individual in the context of the community rather than health care providers (HCP) and the environment for several reasons. First, as extensive health research has documented, the mere availability of health services, including physicians' recommendations of procedures, does not ensure patient uptake of those services.¹⁹ Uptake of services is influenced by more than simple availability and also involves norms, beliefs, and current health practices. Second, FMM focused on the individual in the community context because many of the HCP and environmental characteristics implicated in inadequate cervical cancer prevention are not particularly amenable to extensive modification (eg, inadequate practice time, particularly in rural healthcare shortage areas, difficulty scheduling appointments, a poor public transportation system, concerns about privacy and quality of care at the local health department, and a lengthy waiting time at the provider's office).²⁰

Although many of the patient characteristics associated with barriers to cervical cancer prevention activities, including lower education and income, are also nonmodifiable,^{21,22} individuals' behaviors and the influence of their communities increasingly are recognized as vital elements in optimizing health.²³ Thus, rather than perceiving Appalachia solely in terms of its challenges to health care, FMM has taken an assets approach and integrated strengths that have supported and sustained communities in Appalachia for centuries.²⁴ Two such assets in the Appalachian context are the church and the strong tradition of social networks, particularly among women.

Community Assets Underlying the Intervention: Appalachian Church/Faith-Placed Interventions and Social Networks/LHA Interventions

The rural Appalachian Church and faith-placed interventions. Preliminary work in the Appalachian region has demonstrated the central and sustainable place of the church; such institutions are viewed as culturally acceptable environments in which to gather and promote positive health behavior. The vast majority of families in the region maintain a membership in a church and well over one third of residents indicate that they attend church at least once per week.²⁵ Additionally, recent evidence refutes the assumption that religious communities promote negative constructs like fatalism or lack of self-efficacy.²⁶ For the past 2 decades, faith communities have been selected as a primary setting and/or partner for the delivery of health educational messages and interventions, most especially in African American faith organizations.^{27,28}

Despite the successes of many of these programs, there are very few published research articles on interventions for rural whites within faith communities.²⁹ This absence of such intervention activities in predominantly white rural communities represents a lost opportunity for several reasons. First, many of the disadvantages experienced by African Americans in both rural and urban settings also exist among rural white communities, especially in the under resourced Appalachian region. Furthermore, in both rural white and African American communities, religious institutions have taken center stage as one of the few empowering and self-directed entities.³⁰ For many small, poor, rural communities, churches are among the sole locally-owned infrastructure and play a central role in community life and information sharing. Finally, many Appalachian middle-aged and older women are actively involved in churches, enhancing the likelihood of participation in a faith-placed program

Social Networks and LHA Interventions

Older rural women, who may be less integrated into the health care system, often rely on social networks for information, especially information related to health.³¹ For these women, the church and other social network opportunities may provide trust and familiarity essential in promoting cervical screenings. These social networks, particularly those operating in faith institutions, have been shown to enhance health promotion activities.³² For example, in one cardiovascular intervention, participants in a faith-placed program reduced their body weight by 2.8%, and 65% sustained this weight loss after 6 months. When asked which program components were critical to losing weight, participants mentioned that social support was the most helpful aspect of the intervention.³³ In the Appalachian context, social networks intersect with faith activities through community outreach programs, including health and social service outreach, interdenominational cooperation and organization, and ministerial associations. For many in Appalachian religious communities, “personal ties among church networks are trusted, familiar points of reference” (p. 48) that lead naturally to the acceptability of interventions.²⁹

Developmental work for this project indicated that a lay health advisor (LHA) intervention might bring together social networks, faith communities, and health promotion. Such interventions have demonstrated successes in educating women on the need for Pap smears, decreasing distrust about the health care environment, and providing suggestions on overcoming barriers experienced.³⁴ LHA programs have been shown to be especially useful for hard-to-reach populations because these populations are often excluded from key facilitators of cancer screening services, including physician referrals, educational enrichment, and positive patient-physician communication. Additionally, traditionally underserved women have been shown to draw heavily on the input from their peers, thereby laying the groundwork for the acceptability of LHA programs.³² For rural women, LHAs have been particularly helpful in tailoring information about area resources to specific community barriers.³⁵⁻³⁷

METHODS

Development and Implementation of Faith Moves Mountains

Early development. Faith Moves Mountains was designed to increase adherence with recommendations for obtaining Pap tests. The project was developed through an 18-month process that included ethnographic and survey research in communities in Appalachian Kentucky. During this phase, the team developed the “Faith Moves Mountains” project name, reflecting a local sense of place (residents refer to themselves as being from the mountains rather than Appalachia). Faith Moves Mountains also highlighted the central role of religion, referred to a biblical adage, and ensured discretion with the health topic (by not mentioning cervical cancer). The project team also undertook several distinct activities to inform the intervention, including interviews with women rarely or never screened for cervical cancer, a survey of church women, confirmatory focus groups, a community inventory, and interviews with key informants. All activities, in both development and intervention phases of the research, were approved by the university’s institutional review board.

During 25 interviews with rarely or never screened women, approximately 70% said that they were “very likely” to attend their church at least twice a month. Participants mentioned the following reasons why churches would be useful intervention sites: (1) frequent attendance by targeted population group, (2) generally strong feeling of trust and reliability, (3) established precedent for health discussions, (4) existing health and women’s ministries, (5) availability of child and elder care, (6) trust by male family members, (7) no worries about financial costs or being taken advantage of, and (8) local control. A survey of 72 Appalachian women from faith organizations revealed that over 75% of the women were age 50 and older and 38% of those aged 50 or older reporting not having Pap smears within the past 3 to 5 years. Nearly all

(82%) reported that they would be interested in participating in a cervical cancer education program through the church if one were offered.

Finally, the team conducted a series of confirmatory focus groups, a community inventory to identify regional assets and barriers (eg, transportation, telephone, health clinics, etc.), and in-depth key informant interviews with health care and service providers and ministers. These activities improved understanding of recruitment and retention; the resources of the local communities; and methods for working with religious, social, and health service organizations; these activities also shaped the content of our educational and lay health advisor interventions. Two published articles emerged from this phase of the project, as well as a refinement of the protocol.^{17,38} Both of these articles update the literature on Appalachian women's perspectives on determinants of cervical cancer screening.

Theoretical Basis

As shown in Figure 2, Faith Moves Mountains drew on the strengths of several conceptual frameworks, including the PRECEDE-PROCEED and social cognitive theory (SCT), and principles of community-based participatory research (CBPR). PRECEDE-PROCEED facilitates the identification of many different classes of factors—predisposing, enabling, reinforcing, and need—that influence health and health behaviors, focusing on social, epidemiologic, behavioral and environmental, and educational and organizational views of a health problem within a community context.³⁹⁻⁴¹ The key predisposing factors that FMM focused on include knowledge, self-efficacy, and attitudes.

Although PRECEDE-PROCEED provided a general framework for intervention development and implementation, SCT provided direction for the specific elements of intervention.³⁹ The focus on LHAs as culturally consistent role models followed years of effective interventions in traditionally underserved rural populations.^{42,43} Educational input from the lay health advisors addressed the need aspect of our program; LHAs provided extensive input on the screening recommendations and efficacy of Pap tests. Enabling factors were a major focus of Faith Moves Mountains, with a tailored newsletter and counseling session that addressed barriers specified by participants (eg, finding free/low-cost screenings, connecting with the health department, contacting public transportation services) and reinforcements through continuing contact with the FMM staff.

As a community-based participatory research project (CBPR), FMM also employed key principles including ensuring that the focal issue and approach converge with community needs and priorities, locating project resources within the community, sharing key decisions between community members and the scientific community, and providing extensive opportunities for research training.²⁴

Implementation Plan

This faith-placed lay health advisor intervention has been conducted in 5 stages: recruitment of the faith institution and eligible women; baseline interview; educational workshop; follow-up 1 interview; lay health advisor face-to-face, tailored home visit; and final follow-up/exit interview. The delayed-intervention group followed the same process, except the intervention component was delayed approximately 4 months and an additional assessment was inserted prior to the intervention. Figure 3 displays the sequence and timing of intervention activities.

Community networks—An integral part of the development of a LHA program involved drawing on the social resources and networks of the community, a task that would not be feasible without well-connected and highly regarded local personnel. After an extensive and time-consuming search for an experienced, highly respected, and thoughtful local project

manager, staffing and tailoring the protocols became local decisions; the project manager selected her assistants, interviewers, and lay health advisors and, with consultation with the entire team, molded the conduct of the educational and tailored home visits to conform to local norms. Similarly, initially, the scientific team provided training in human subjects, interviewing, and project protocol through formal sessions, testing, and standardized manuals; however, early in the project these responsibilities were assumed by the professional community staff.

Consistent with the overall orientation of the project, as many operational decisions as possible were made on the local level, including personnel (eg, identifying and hiring a computer technician or graphic designer), selection of appropriate printed educational materials (eg, highlighting local images and suitable resources), and implementation of the intervention procedures (eg, opting for face-to-face recruitment rather than via mail or making follow-up check-in phone calls for greater individual attention). Ensuring that local communities take primary ownership of the project reaps multiple benefits—enhancement of the knowledge and expertise of the community, improved development of community infrastructure, provision of employment and training opportunities, and stronger likelihood of an acceptable program.⁴⁴

Recruitment protocol (Faith Communities)—FMM drew on a variety of faith communities—white and African American, large and small, nondenominational and mainline churches and faith-related activities (outreach in Bible studies or food pantries) to help find and recruit this hard-to-reach population.

Initially, the study was designed to obtain a stratified (by one of 4 counties) simple random sample of faith-based organizations in the catchment area. Ultimately, identification of organizations via random sampling and eventual contact either by postcard, phone, or visits from our project office in eastern Kentucky, proved to be futile as only a handful of churches randomly selected were able to be contacted and ultimately showed interest. The recruitment protocol focus was then changed from using a randomly shuffled comprehensive list of organizations to a protocol that called for taking advantage of established connections to organizations for which our field staff had personal connections. The initial focus was on recruiting organizations within the county of residence of our field office. This approach met with immediate success, and acceptance of the program enabled churches to be recruited in the same manner in the remaining 3 counties.

Our project staff made a contact with the church's leaders (minister, lay people, minister's wife) to describe the project. Discussing the project often took several meetings; however, FMM has had a 90% success rate in church recruitment, mainly attributable to the local staff's expertise, excellent reputation in the community, and increasingly positive word of mouth about the project. In addition to visits with church representatives, FMM staff frequently attended church services and special events.

Currently, the project has recruited 30 churches with the following denominations: 3 (10%) mainline protestant (AME, Presbyterian, Methodist, etc); 13 (43%) Baptist and Anabaptist (Southern Baptist, Freewill Baptists, Old Regular Baptists, Missionary Baptists, etc); 10 (33%) non-denominational, Evangelical, Pentecostal; and 3 (10%) Holiness or Nazarene. These denominational representations are nearly identical to the population of congregations in the 4 counties in which Faith Moves Mountains operates. "Other groups," including Latter Day Saint, Catholic, and Jehovah's Witness congregations, compose 3.7% of the religious affiliations in the project's 4 counties. Thus far, the project has recruited one of these groups (Catholic) into the project.

Intervention participants—After recruiting congregations, FMM staff focused on eligible participant recruitment. Collaborating with church personnel, team members arranged a date for an educational workshop to interested church members prior to which recruitment and the baseline interview occurred. Although any interested person was invited to attend the presentation, our staff members specifically requested the participation of eligible women (40-64 years of age, rarely or never screened for cervical cancer).

Nearing the completion of the project, the FMM team has recruited approximately 420 rarely or never screened women, with 10 women dropping out prior to completing the protocols. The average age of the women is 52 years. Reflecting Kentucky Appalachia, most participants are white (93%) and married (60%). Just under half (43%) have more than a high school education. Nearly half of the women work outside the home (49%); however, about 25% have annual family incomes under \$10,000, and more than half (53%) selected the subjective assessment statement “I sometimes struggle to make ends meet.” At least half of the women describe their health as either very good or good despite half of them reporting having heart disease or high blood pressure; 20%, diabetes; and more than 30% report having at least one other chronic disease. Regarding their last Pap test, approximately one quarter (24.7%) had a Pap test 3 years ago; half (45.5%) indicated it had been over 3 but under 5 years ago; 29% reported receiving a Pap test 5 or more years ago; and less than 1% (.7%) had never had a Pap test.

Interview and intervention protocol—For those eligible and willing to participate, informed consent documents and a pilot tested, baseline questionnaire were administered. Our local team offered to orally administer all documents throughout the project in order to avoid problems associated with limited literacy. In addition to current state of Pap receipt and staged readiness to receive the test, baseline and follow-up interviews include sociodemographic questions, a cervical cancer-specific instrument,⁴⁵ a cervical cancer-specific knowledge questionnaire and barriers assessment,⁴⁶ a measure of decisional balance,⁴⁷ and self-efficacy for cervical cancer-related activities and stages of readiness for Pap test receipt.⁴⁸ The project relies on self-report for receipt of Pap test for several reasons. First, with most studies demonstrating approximately 70% positive and 95% negative predictive value of recall for Pap tests,^{49,50} self-report tends to be acceptably predictive of Pap receipt. Second, FMM resources are too limited to undertake medical records review. Third, medical records review likely would undermine trust.

Those in the intervention group receive a culturally tailored educational program about cervical cancer, Pap tests, and local resources that may facilitate screening. Cultural tailoring, undertaken primarily by lay health advisors (LHA), has been accomplished in several ways. First, simply by having LHAs—local women selected because they are well integrated into the social and religious life of the community—the program acknowledged the importance of local traditions and insider status. In addition, cultural tailoring was put into place as the LHAs and other project staff guide intervention development and delivery, including reviewing and revising questionnaires, intervention protocols, and the tailored newsletter for appropriateness and meaning.

Approximately 5 to 10 weeks after the educational intervention, the participants received a second interview to assess any changes in stage of readiness, knowledge base, and perceived barriers to receipt of Pap tests. Two to 3 months after the second interview, participants receive a home visit from a local, trained LHA, who, prior to the session, reviews the participant’s specific barriers to Pap tests and creates a custom-made information packet. Interviewers obtain responses about these barriers (ie, transportation problems, lack of health insurance coverage, conflict between clinic hours and employment) during each participant’s baseline interview. This packet, consisting of a tailored newsletter and a “contract,” comprises the basis for the LHA visit.

The Faith Moves Mountains newsletter is culturally and personally tailored. Culturally, there are local touches including appropriate local references, photos, and descriptions of facilities and services unique to the participant's community. Personally, the newsletters discuss each participant's specific barriers to Pap tests and suggest resources to overcome these challenges. This process of LHAs' incorporating stated barriers into the newsletter and then reviewing the newsletter with the participant in a nonthreatening home environment ensures that the intervention is stage-matched and its language and delivery style are acceptable to community members.

Two weeks later, the participant receives a telephone follow-up call from her LHA, asking whether she has experienced any barriers to receiving a pap test and has any questions. Two months later, the participant has her final or exit interview in which she is asked about whether she has received a Pap test or plans to, which (if any) portion of the intervention had an influence on receiving a Pap test, and overall satisfaction with the program. This entire process is repeated for the delayed-intervention group, with the addition of one assessment immediately prior to the LHA intervention. During this assessment, FMM staff determine whether the delayed participant, who is serving the function of a control group member, has received a Pap test (and when and what precipitated the decision).

Evaluation Plan

Faith Moves Mountain's evaluation involves a mixed-method approach. Qualitative and quantitative analyses of in-person interviews and questionnaires allow a description of the program experience and satisfaction and detects changes in knowledge of cervical cancer and receipt of Pap tests. Debriefing qualitative process evaluations involving exit interviews are being conducted with a randomly selected set of participants, all LHAs, and a subsample of key informants to determine their experience and satisfaction with the intervention, consistency with programmatic goals, potential contamination, and costs.^{2,51} The quantitative evaluation focuses on the main outcome measure, receipt of Pap smear, in addition to several moderating factors such as (1) knowledge of cervical cancer and Pap tests, consistency with recommended intervals for screening, and perceived efficacy of the screening tests and mediating variables; (2) decisional balance; and (3) self-efficacy.

CONCLUSIONS AND FUTURE DIRECTIONS

This article has described a health education program designed to decrease the burden of cervical cancer among Appalachian women by increasing Pap test use. Currently, 421 rarely or never screened women have completed a baseline interview and educational workshops. Most participants (355) have completed their follow-up 1 interview; 248 have had the lay health advisor face-to-face, tailored home visit; and 119 have completed the entire protocol, including their exit interview.

Faith Moves Mountains draws on the assets of local communities—strength of social ties, respect and trust afforded to faith institutions, and the dynamism and commitment of local citizens to improve the lives of others—in combination with scientific frameworks and principles. Such frameworks and principles include the SCT, PRECEDE-PROCEDE models as well as community-based participatory research concepts. From the 4 years working in the central Appalachian communities of Kentucky, the FMM team has drawn several conclusions.

First, planning for and early administration of the intervention required multiple learning paths. Prior to the planning of Faith Moves Mountains, many community members did not realize the disproportionate burden of cervical cancer shouldered by their community, a realization essential to increase community empowerment and motivate action. Early efforts in enlisting the support of churches, social service agencies, and key individuals in the community required

our team to demonstrate the health disparities of cervical cancer. Once explained, many community members embraced the project's goal of early detection. Similarly, the community-based staff worked hard to educate the scientific staff on the rather extensive modifications to the research design necessary for community acceptance. For example, the proximity of congregations, the frequent trips made across county lines, and the strong connections of many in the region required rethinking of a standard control and experimental group design. Ultimately, FMM adopted an early- and delayed-intervention approach.

Like most CBPR-based interventions, this project has modified its design and conduct to conform to community expectations, logistical requirements, and budget reductions. For example, as described in this article, initial plans for randomized recruitment of faith institutions yielded to sampling that is more productive and remains representative of the denominational distribution in central Appalachia. Once staff realized that mailed invitations soliciting participation in the project were being "returned to sender" or remaining unopened on already overcommitted preacher's desks, they took a personal, door-knocking approach. Beyond that, team members attended church and participated in numerous outreach programs. Initial plans to make data collection more efficient by using laptops in the field took a different direction, as interviewers preferred to hand-enter data and double-check for quality assurance, placing less distance between them and the participants and engendering more trust. Finally, although the project sustained a sizable budget reduction and had to reduce the scope of work, the team has been able to strategize to operate on lean resources, something well known to residents of eastern Kentucky. Such tweaks and modifications have resulted in more appropriate and acceptable practices while remaining true to research design and objectives.

Another conclusion the team has drawn pertains to planning for the next health promotion project. During the formative research and throughout project implementation, FMM staff has remained vigilant about health concerns expressed by a wide array of community members, positioning the project to respond to community input as well as subsequent project initiatives. Such receptivity aligns closely with principles of CBPR.^{24,44} Over the next half year, FMM will complete our recruitment and finalize their program activities. Although early results look promising, research activities must draw to a close prior to any definitive conclusions about the efficacy or effectiveness of Faith Moves Mountains.

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**Cancer Mortality Rates by County (Age-adjusted 1970 U.S. Population)
Cervix Uteri: All Races, Females, 1970-1998**

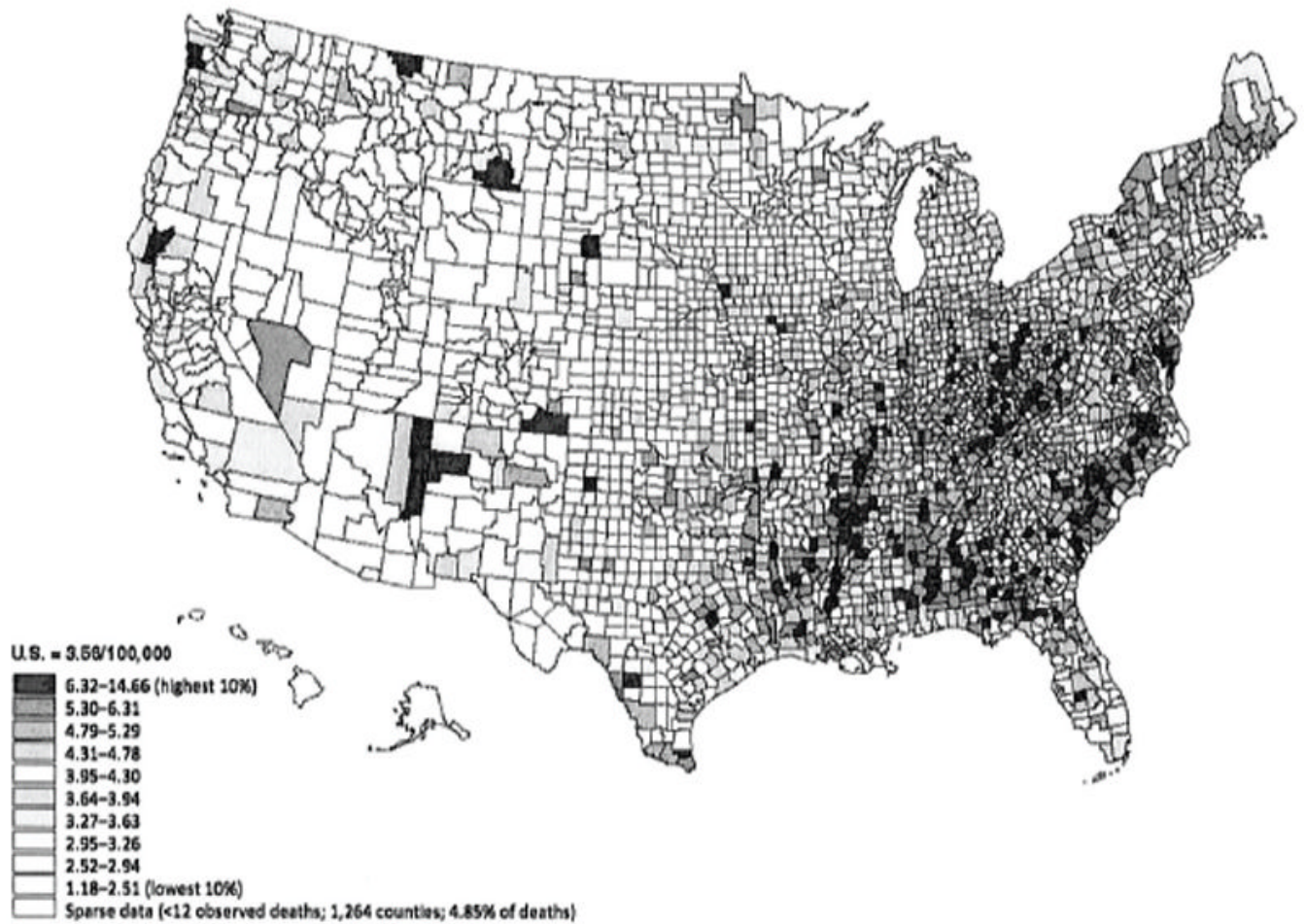


Figure 1.
Cervical Cancer Mortality Rates by US County, 1970-1998 (Source¹³)

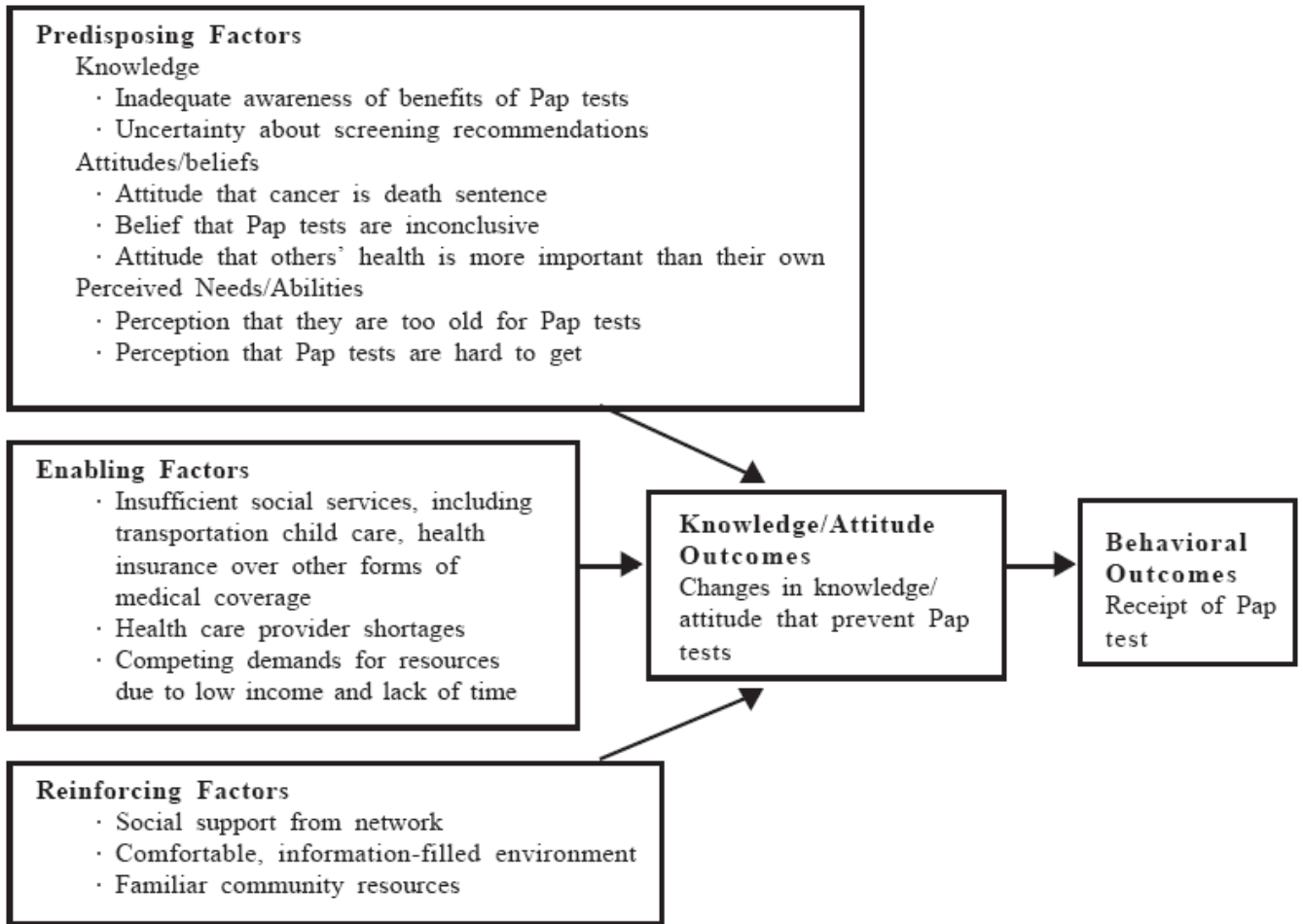
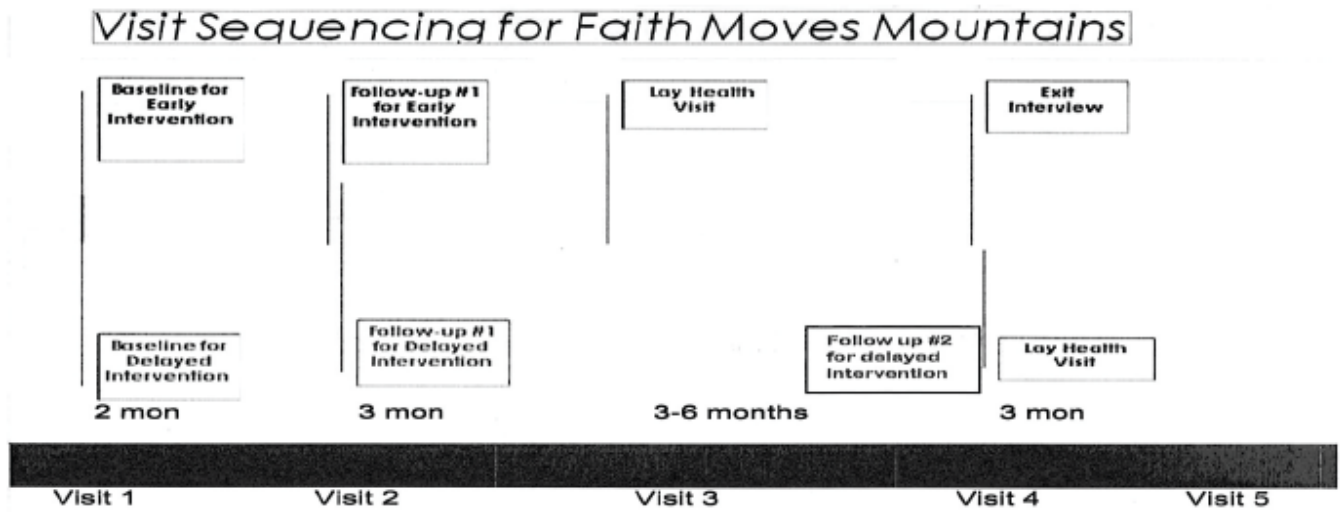


Figure 2.
Summary of Factors Based on Theoretical Models Influential in Receipt of Pap Test



Uppercase Delayed Intervention in Visit 4.

Figure 3.
Faith Moves Mountains Intervention Sequence

Table 1
 Kentucky and Within State Comparisons of Pap Smear Screening, 1999-2000^{54,55}

	Ever had Pap			Never + >3yrs
	Ever had Pap	Pap in last 3 yrs	Pap >3 yrs	
US	94.8%	87.4%	11.4%	16.6%
Kentucky	92.1%	86.5%	12.6%	20.5%
Appalachia	90.8%	84.5%	14.8%	24.0%
Non-Appalachia	92.6%	87.3%	11.8%	19.2%
< 50 yrs.	94.2%	92.5%	7.2%	13.0%
≥ 50 yrs	89.2%	77.5%	20.7%	31.5%