

**Noncompliant Behavior for  
Colposcopy Examination  
in Women with Abnormal  
Pap Smears**

**by**

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Reader's Approval

Salisbury State University School of Nursing

This is to verify that Lisa H. Bayles successfully defended her Master's thesis entitled Noncompliant Behavior for Colposcopy Examination in Women with Abnormal Pap Smears September 9, 1994.

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## Abstract

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The purpose of this study was to describe, through a qualitative approach, the emotional, physical, and psychosocial barriers experienced by women who are non-compliant with their scheduled colposcopy exams. The objectives were to describe from the women's own perspective what they experienced when receiving abnormal Pap smear results, to explore the barriers experienced to colposcopy by non-compliant women, and to conceptualize without the bias of race, age, or socioeconomic status, common causes of non-compliance in women. It is hoped that programs can be developed and tested that would address barriers to colposcopy and result in successful increases in compliance.

The sample consisted of six women noncompliant for colposcopy after receiving abnormal Pap smears. Three participants received their gynecological health care from private physicians, one from a non-profit private organization, and two from a local health department. Data were collected prior to the participant's rescheduled colposcopy exam using an open-ended questionnaire similarly structured for all interviews. Data analysis was done through transcriptions of the interviews and coding of common concepts. Five categories describing the emotional,

physical and psychosocial barriers emerged from 20 codes. Validation of the codes and categories was accomplished through confirmation interviews with two of the six participants, the thesis chair and input from an experienced ethnographic researcher.

Five categories emerged from the data: fear, denial, social and self influence, lack of knowledge and physical obstacles. They comprised the experience of having an abnormal Pap smear and noncompliance for colposcopy for the six participants. The categories of fear and denial contained the emotional response to the abnormal Pap smear and the colposcopy procedure. The category, social and self influence and lack of knowledge, elicited psychosocial influences for colposcopy compliance. The category, physical obstacles, consisted of physical and psychosocial barriers to compliance for colposcopy examination. It is important for nurses to consider the individual impact of having an abnormal Pap smear and be aware of the multitude of emotional, physical and psychosocial influences for compliance to colposcopy and to tailor his or her counseling to meet not only the woman's informational needs but her emotional needs as well.

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September 9, 1994

Date

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## Chapter I

There will be 15,000 new cases of cervical cancer diagnosed this year and 4,600 deaths, according to the American Cancer Society (1994). If the disease can be caught at the pre-cancerous state (in-situ or earlier) the chances of survival are virtually 100 percent (American Cancer Society, 1993). Howard (1987) found that even though the incidence of cervical cancer has dropped in the last forty years invasive cancer of the cervix has been increasing in younger women.

Early detection and treatment of cervical cancer can decrease mortality and morbidity (Lerman, Riner and Engstrom, 1991; Guntoli, Atkinson, Ernst, Rubin and Egan, 1985). The Papanicolaou (Pap) test was introduced by George N. Papanicolaou in 1924 and since the 1950's has been the most effective primary screening tool for the detection of cervical cancer (Koss, 1989; Stafi, 1990). A Pap smear is a sampling of cells obtained from a woman's cervix with a wooden spatula and a cotton-tipped applicator or a cytobrush. The cells are smeared onto a glass slide and preserved with a fixative. The slide is then examined microscopically by a cytotechnologist or a pathologist for changes indicating various abnormalities.

An abnormal Pap test can be defined as any cytological findings other than normal. Reports can range from

inflammatory changes to atypia, dysplasia, carcinoma in-situ (CIS) or malignancy, with varying sub-categories in between. Chatelain, Schunck, Schindler, Schindler, and Böcking (1989) found in their study that "the mean progression time from mild dysplasia to CIS is approximately 5.8 years and from moderate dysplasia to CIS is 3.1 years" (p. 509). It has also been shown that progression to malignancy can occur much more rapidly. The human papilloma virus (HPV) can create precancerous lesions and lead to cancer in a few short years (Reid and Greenberg, 1990; Chatelain, Schunck, Schindler, Schindler and Böcking, 1989). The exact number of years from infection to development of cancer cannot be stated since each person's immune system varies.

Colposcopy is fundamental for screening and detection of procursive lesions and other cytologic changes of the vulva, vagina and cervix. With the use of colposcopy, lesions not visibly detectable can be diagnosed, evaluated and treated, leading to a decrease in morbidity and mortality (Giuntoli et al., 1987).

The colposcopy exam is performed by a trained clinician. The cervix is viewed through an instrument called a colposcope (hence the name colposcopy) which magnifies the cervix, enabling the clinician to evaluate the tissue for abnormal changes. Frequently a colposcopically directed biopsy may be taken from the abnormal area and

examined for changes significant of precancerous lesions. Results of this biopsy are much more conclusive than of the Pap smear. Based on the biopsy findings, treatments are recommended and performed to stop the progression of the disease.

#### Statement of the Problem

Participation in regular screening, and for women with abnormal cervical cytologies, a high level of compliance with medical recommendations are two key elements in successful Pap screening programs. Without treatment, women are at a high risk for the development of cervical cancer (Michielutte, Diseker, Young & May, 1985).

A study by Paskett, White, Carter, and Chu (1990, p. 631) reported that "less than 60% of women with diagnosed cervix abnormalities on Pap smear return for follow-up in a timely manner." Not only is this high risk health behavior, but it also increases the cost of health care. Follow up on noncompliant clients is expensive in both employee costs and time management.

Women at highest risk for developing cervical cancer are also at highest risk for noncompliance with recommended medical follow up (Howard, 1987 and Koopmanschap, 1990 and women who are asymptomatic (as in most abnormal cervical cytology) will be least likely to have follow up exams (Lane, 1983). Noncompliance after a positive cervical

cytologic screening is a significant behavioral problem (Lerman, 1991). Understanding why women fail to follow up on abnormal Pap smear results is important since early detection is fundamental to cancer control (Burack and Liang, 1987). In order to improve services, relevant barriers to early detection must be identified.

Notification of abnormal Pap results creates fear and anxiety in women, which, along with other factors, can play a role in their decision not to follow through with their health care provider's recommendations. Few studies have been done on compliance with follow up treatments for women with abnormal Pap smears. The nurse and other members of the health care team need to be aware of the woman's feelings toward the Pap results, the recommended treatments, and personal factors that are a part of her decision to comply. Through an understanding of these influences, program protocol, notification procedures, scheduling procedures, and follow-up can be tailored to fit those women's needs, therefore improving compliance and decreasing cervical cancer morbidity and mortality.

#### Purpose of the Study

The purpose of this study was to describe, through a qualitative approach, the emotional, physical, and psychosocial barriers experienced by women who are non-compliant with their scheduled colposcopy exams. Studies

have been done to determine fears and anxieties women experience when notified of an abnormal Pap smear, and efforts have been made to increase compliance through development of new approaches. Yet, there is a paucity of studies that look at all the issues and feelings that influence a woman's decision to ignore the recommended treatments for colposcopy.

Nursing practice today is described as holistic, viewing patients as a whole and recognizing that all behavior has meaning. It is the intent of this research to explore with the noncompliant woman her perceptions of her abnormal Pap, how she reacted to the results and why; and to gain an understanding of her behavior through her experiences. Studying the noncompliant woman with respect to her viewpoint opens up the research to include all influences in her experience, rather than subjecting her to studies of varying parts of her experience which are then pieced together. "The nursing profession advocates the individual as author of his own world; definer of his own reality. The goal is a nurse-client collaborative effort in health care" (Oiler, 1982, p. 178).

#### Research Objectives

The first objective of this descriptive qualitative study was to describe from her own perspective what a woman experiences when receiving abnormal Pap smear results.

To ensure that this experience was investigated as it was truly experienced, "bracketing" was used to approach the study, with no preconceived ideas from past experiences, literature or theoretical frameworks. "Bracketing" allows one to suspend or set aside any preconceived ideas, thoughts or feelings about the experience studied (Knaack, 1984; Omery, 1983; Oliver, 1982).

The second objective of this study was to explore the barriers experienced by non-compliant women with abnormal Pap smear results. Data was to be collected in a manner that would enhance spontaneity. By taping the interviews, both the researcher and subject were free to converse and explore those reasons for noncompliance expressed by the subject.

The third objective was to conceptualize without the bias of race, age, or socioeconomic status, common causes of non-compliance in women. From the study's findings, it is hoped that programs can be developed and tested that would address barriers to colposcopy and result in successful increases in compliance, thus decreasing the incidence of invasive cervical cancer and increasing the survival rates of women at risk.

The research objectives were guided by, but not limited to, the following questions:



1. What are the feelings women experience when notified of abnormal Pap smears?
2. How are those feelings expressed?
3. Do women of different race, age, and socioeconomic characteristics experience common feelings?
4. What do those women need to know to understand their Pap results?
5. What influences their decision not to comply with recommended follow-up procedures?
6. What can health care providers do to break down barriers to compliance?

#### Theoretical Base for the Study

The theoretical base underlying this study is phenomenology, "an approach to human inquiry that emphasizes the complexity of human experience holistically as it is actually lived" (Polit and Hungler, 1991, p. 651). Previous research has focused on parts of the problem of noncompliance with few attempts to look at it as a whole. Giordano and Dersek state it best, "Since health behavior change must encompass the physiologic, social, psychological, emotional, and spiritual aspects of the individual, the outcomes of change programs must be based on all of these aspects in a synergistic manner" (1988, p. 15).

This research attempts to describe the experience of women with abnormal Pap smears and their fears and feelings

that evoke noncompliant behavior. Oiler (1982) promotes the phenomenological perspective in nursing research. She describes four themes within this framework. Phenomena, in which one sees the world and its objects and events as they appear, is the first theme. Noncompliance is a behavior but to study just the behavior is to overlook all the co-existing factors contributing to the experience of the woman with an abnormal Pap.

Reality is the second theme. "For phenomenologists, reality is a matter of appearances" (Oiler, 1982, p. 178). Subjectivity, in which "the work becomes real through contact with it," is the third theme (Oiler, 1982, p. 178). The phenomenologist tries to see the experiences of individuals through their eyes, not through his/her preconceived idea.

Truth is the fourth theme. The phenomenological researcher looks at human expression through subjective data and utilizes many resources not used in the scientific approach. It is up to the researcher to "locate appropriate sources, boldly and creatively" (Oiler, 1982, p. 179), collecting data from letters, diaries, and personal conversations, for example, to discover how the person or persons truly feel about an experience as they see it, without imposing the researcher's concept of how the person should feel on the data.

### Research Methodology

A qualitative, descriptive approach was used as an attempt to build on existing knowledge through a phenomenological framework. Phenomenology is a philosophy and an approach to research that attempts to study human experiences as it is lived (Omery, 1983). Nursing is "holistic," which means we care for individuals as they are in their environment. Concepts such as fear, anxiety, or anger are a part of human experience. To truly understand those concepts, research must approach them in a manner that enables one to look at the experience without pre-conceived ideas. Qualitative methods are undertaken based on the goals of describing reality or developing theory about everyday experience" (Porter, 1989, p. 100). By listening to women describe their feelings about their Pap smears, a deeper understanding of those feelings can be found.

Imposing structure on the research restricts the subjects' responses to the researcher's preconceived categories or options, which may result in missing other valid responses and distorting reality. Qualitative research not only considers the person holistically, but also attempts to study the experience as it is occurring to or felt by that person. By choosing the descriptive method of qualitative research, the researcher attempted to understand what and how women feel about abnormal Pap smears

and the colposcopy procedure. To be able to describe the feelings would provide further insight into noncompliance for colposcopy.

The concept of "noncompliance" has been frequently referred to in this thesis. Continued use of this term requires a definition. Michielutte et al. (1985) defined noncompliance as failure to respond to notification of an abnormal Pap smear by failing either to make a follow-up appointment or to keep such an appointment after it was made.

The concept of "abnormal Pap smear" can have many meanings and definitions. For this study, abnormal Pap smears are cervical smear results showing chronic atypia, dysplasia, in-situ and/or changes suggestive of HPV.

## Chapter II

## Review of Literature

In qualitative research the literature review is held until completion of data collection and analysis. This is to reduce bias other research could create for the researcher. Some research is done prior to data collection to enable the researcher to understand the problem. "Bracketing" is then employed to eliminate potential bias by the researcher.

Compliance has long been an issue in health care. Young stated "as long as there are health professionals giving advice, there will be a need for strategies to improve compliance" (1986, p. 31). Numerous researchers have attempted to explain various aspects of compliance/noncompliance by theorizing why patients do not follow through with recommended health care, and assessed methods to improve compliance. Little research was found focusing specifically on noncompliance for colposcopy. A great deal was found studying reactions to abnormal Pap smears and feelings women had about the colposcopy exam.

Research about abnormal Pap smears and colposcopy discussed here will focus on topics such as information sought by women to understand the Pap smear results, how information seeking contributed to compliance for follow up, emotional response to abnormal Pap smear results and

assessment of various frameworks formulated to explain noncompliant behavior. Most of the research is quantitative with few qualitative and survey type methodologies.

This literature review will be broken down into three categories of research on the compliance issue: colposcopy abnormal Pap smears, and other relevant research collected to understand the compliance issue. They will be in chronological order in each section, beginning with earlier studies to most current.

#### Coloscopy Research

In 1983 Miller and Mangan conducted a quantitative study about differences in coping between persons desiring information (monitors) about a negative event (in this case colposcopy and abnormal Pap smear results) and persons preferring little information (blunters), and how this affects their level of stress. Forty-four patients were interviewed prior to their colposcopy exam. They were divided into two groups, those desiring information called monitors and those preferring little information called blunters. Determination of behavior style was done through the Miller Behavioral Style Scale, which divides subjects into monitors and blunters based on self-reported preference for or against information. Half of the monitors and half of the blunters were given detailed information about the colposcopy procedure. The remaining half of the two groups

were given little information. The participants coping and stress level were measured before, during and after the exam through pulse readings, observation, and self-rated mood.

Miller and Mangan found that those participants given more information showed higher levels of tension, depression and discomfort during the phase prior to the colposcopy exam, regardless of coping style. High-information participants' level of tension decreased by the end of the exam, but levels of depression and discomfort remained the same. Even up to five days after the exam, the high information group continued with higher levels of depression and discomfort compared to the low information group. This finding supports future studies (Barswick and Johnson 1990; Lauver and Rubin, 1990; and Lauver, Barsewick and Rubin, 1990) which found no differences or changes in anxiety levels when women are given information about the colposcopy procedure and an explanation of test results.

Differences between monitors and blunterners given high and low levels of information revealed blunterners do much better when given less information. The monitors showed some reduction in stress when given high levels of information compared to monitors given low levels. The conclusion is that not all patients desire and need a lot of information about negative events in order to cope with the procedure. Health care workers need to be aware of the

individual needs of their patients and provide the level of information needed while still providing informed consent.

Michielutte, Diseker, Young and May (1985) performed a quantitative study to assess for common demographic characteristics of women not complying for colposcopy. After reviewing the records of 177 women with cervical dysplasia of which 17 percent were noncompliant, four significant variables were found in the noncompliant sample. They were more likely to be unmarried, less educated, younger, and with fewer total health problems. The two variables most significant were level of education (greatest significance) and fewer health problems. Michielutte et al. concluded the data cannot be viewed as predictors of noncompliance, but show some similar characteristics for those noncompliant women. Due to the small sample and the sample primarily of a younger age and predominantly black, generalizations cannot be made.

In an attempt to describe the emotional impact of abnormal Pap smears on women referred for colposcopy, Beresford and Gervaise (1986) conducted a qualitative descriptive study on 50 women referred to a hospital based clinic for colposcopically directed biopsies. The initial interview was performed prior to the procedure after receiving an explanation about the Pap smear results and the colposcopy procedure. After the procedure the hospital



psychologist interviewed the women again, using open-ended questions, to determine their feeling about the Pap smear. Four major responses occurred. They included (1) fear of cancer (100% response); (2) fear of loss of reproductive/sexual function (68% response); (3) fear of medical procedure (65% response) and (4) fear of bodily betrayal (62% response) described by the researchers as "the first realization in young, typically healthy women that their bodies might not be functionally perfect and under their direct control" (p. 85). Beresford and Gervaise's study was limited by not distinguishing feelings between the Pap smear, the colposcopy procedure and the results. The psychologist could also influence the responses just by the fact of being a psychologist, possibly creating an atmosphere of analysis and reducing the subject's ability to express their feelings for fear of having the "wrong" feelings labeling their response as needing psychiatric intervention. The findings do support later research on emotional responses to abnormal Pap smears and follow up recommendations.

Emotional responses were again studied by Barsevick and Johnson (1990) in their study of information-seeking efforts during the experience of colposcopy. The aims of their study were to examine what information was sought by women during colposcopy, to determine if those seeking information

also possess a preference for information and involvement in their health care, and to determine if women seeking information experience more positive and fewer negative emotional responses. This study attempted to build on existing research predicting those persons seeking information will have less anxiety about the procedure and those not seeking information will have more. The study sample was predominately white with some college education. Surveys were done seven to ten days prior to the exam, just prior to the exam and during the procedure.

It was found by Barsevick and Johnson women reporting a higher preference for information also asked more questions during the exam. The results also supported the study hypothesis that those who show a preference for involvement in their health care also seek more information. Women who asked more questions during the clinic visit were found to have more confidence after the examination. No association was found between the number of questions asked, the seeking of information and positive or negative emotional scores, conflicting with the study's theory that more information sought about a negative event decreases the negative emotional responses to the event.

Lauver and Rubin (1990) studied effects of a loss-framed message and a gain-framed message on attendance rate for colposcopy. The sample (N=116) was derived from a

clinic at a large medical center in a northeastern United State's city. A large percentage was black (94%) and on public assistance (82%), with 47 percent having a high school education. When phoned with the abnormal Pap smear results, some were given the loss-framed message (what the women would lose by not attending colposcopy: for example, no test could be done to see what the abnormal cells mean, and the opportunity for early detection of cancer would be lost). Others were given the gained framed message: that they would find out what the abnormal cells mean, receive early treatment, and increase their chances of being cancer-free. At the colposcopy visit an interviewer blind to what type of message the participant received collected data on reasons for attending, feelings of threat, relevant beliefs and optimism. The results of the study revealed that older women, those with a history of a gynecological infection, and those with a history of cancer in the family were more likely to attend. The analysis of the loss- or gained-framed message did not support the theory that differences in message types would affect attendance for colposcopy.

A descriptive qualitative study to determine common questions asked about colposcopy and the results of the exam was done by Barsevick and Lauver (1990). The sample size was small, as is the case in most qualitative research. It included 36 predominantly Caucasian women with a high rate

of college education and employment. The data were collected by the investigator as she accompanied the participants during their colposcopy visits. Information was documented about demographic information, spontaneous questions, and clinical information asked about the colposcopy procedure. The results were broken down into exam related questions and those about the procedure findings.

It was found 52 percent of the questions were exam related, focusing on sensations, what the physician could see, colposcopy procedure, timing of procedure, what the physician did during the procedure, questions about objects in the room, and self-care activities. Results related questions focused on the meaning of the results, treatment options and procedures, and timing of the treatment options and procedures, and timing of the treatments. No questions were asked about treatment sensations or self-care activities related to the treatment. The researchers felt the results were consistent with the self-regulation perspective which reflects a need for information about sensations of procedures, procedural events and self-care instructions. By increasing awareness of the type of information needed and sought by patients for colposcopy and Pap smear results, counseling could be developed which would be much more effective in allaying patients' fears.

Distrust and anxiety have been shown to occur with news of an abnormal Pap smear and subsequent colposcopy. Marteau, Walker, Giles and Smail (1990) measured levels of distress in women recommended for colposcopy as a result of an abnormal Pap smear in a quantitative study involving 30 women attending a hospital-based colposcopy clinic. The only demographic given was their age, an average of 30.7 years. A questionnaire was used to measure the participant's anxiety about colposcopy, what the doctor might find and other specifics related to colposcopy and the abnormal Pap smear. The questionnaire was completed prior to and after consultation.

The results of the study showed a high level of anxiety concerning the colposcopy procedure and what the doctor would find. There was no relationship found between the severity of the Pap results and anxiety level. The three most frequently cited concerns were: would it be painful, would it be uncomfortable and what would happen during the procedure. They did find significantly less anxiety after the procedure. The limitations of this study included a lack of demographics and small sample, resulting in an inability to generalize findings to a larger population as well as difficulty in replicating without further information.

Lauver, Barsevick, and Rubin (1990) continued their research on adaptation to abnormal Pap smears through a qualitative/quantitative study to determine the frequency with which women seek causes or reasons for their abnormal Pap smear. They labeled this behavior "spontaneous causal searching," based on the theory of attribution, which predicts a relationship between increased adjustment to a negative event (abnormal Pap smear) when individuals react by seeking causes to the event. Adjustment was measured by type of expectations for follow up colposcopy, negative affect, and/or promptness of attendance for follow up.

The study sample included 118 women requiring colposcopy for an abnormal Pap smear. The sample was derived from a large urban hospital, and was predominately black and on public assistance. The participants were contacted by phone, given a controlled message about their abnormal Pap smear and offered follow-up appointments. Only one chose not to schedule an appointment but the reason was not provided. At their follow-up appointment, participants were asked to share their initial reaction to their abnormal Pap smear, their expectations for follow-up and reasons for or barriers to seeking the follow up. It is important to note that 12 women who failed to keep their appointment were called and received the same interview. Their responses were similar to those who kept their appointment.

One or more questions were asked by 61.5 percent of the sample. Thirty-four percent asked questions reflecting causal searching. Thirty-seven percent expected a normal diagnosis and only seven percent expected something serious. Fifty-six percent expressed negative emotions such as worried, frightened or scared. Seventy-four percent obtained prompt follow-up within six weeks of notification about their abnormal Pap smear. In conclusion, the researchers found no significant association between causal searching, type of expectations, and negative emotions or attendance for follow-up colposcopy.

Further qualitative studies were performed by Lauver and Rubin (1991) about client informational needs (what questions resulted from having an abnormal Pap smear and subsequent colposcopy exam) and how to assess for reactions to the abnormal Pap smear. Participants were interviewed by phone after being provided with their Pap smear results and again at the follow up exam. A total of 107 participants were interviewed. Questions asked about the Pap smear results and follow up exam were recorded as one aspect of study then using open-ended questions, the participant's reaction to the Pap smear were assessed. The study revealed the most common questions asked upon hearing of the abnormal Pap test results were about further evaluation or causes of the abnormality. Less frequently questions were asked

regarding the seriousness or uncertainty of the purpose and procedure for the Pap smear. Only four participants reflected fear or worry. At follow-up testing the most common concern was about the seriousness or future implications of the abnormal findings. Forty-three percent expressed nervousness, fear, or being upset. Surprisingly, 39 percent expressed uncertainty about the meaning of the Pap smear and what it would indicate. Overall the research found the most common question asked reflected the women's concern for future evaluation.

Another study regarding emotional factors in colposcopy was done by Lerman, Miller, Scarborough, Hanjani, Nolte, and Smith (1991) who evaluated the psychologic effects of receiving abnormal Pap test results, if those psychologic effects remained even after testing, and if psychologic effects were greater for those women that were noncompliant for colposcopy. A comparison of 106 women with normal Pap smear results with 118 women with abnormal results referred for colposcopy was done (sixty-five participants complied with colposcopy). An interview using a forced-choice Likert scale questionnaire was done by phone three months after receipt of the Pap smear results. It was found that those women with abnormal Pap smear results had greater worries about cervical cancer and altered moods than those women with normal Pap smears. Women with abnormal results also



reported problems with daily activities, decreased sexual interest and sleep disturbances. After undergoing colposcopy, participants reported fewer worries, decreased altered moods and no effects on sexual interest. Those participants noncompliant for colposcopy had greater worries, problems with daily activities, mood swings, sleep disturbances and decreased sexual interest compared to those that had normal Pap smear results and those that had colposcopy. According to the researchers, the greatest limitation to this study is its measurement at one point in time only. Other concerns the participants may have had unrelated to the experience studied could influence their psychological state.

An interesting study using women classified as being low socioeconomically was performed by Laedtke and Dignan (1992) to explore demographic differences between compliant and noncompliant women, the referral method for treatment, and assessment for differences in the percentage of women who comply at each level of treatment. The study population was characterized as all women with abnormal Pap smear results over a set 12-month period from 14 countries in northwestern North Carolina. The sample was comprised of 52 women from a large gynecologic health center and 119 from surrounding county health departments. All were notified the same way about their Pap smear results and given an

appointment for follow up. Data were collected from the medical records for demographics and treatment regimen. All women were followed for a minimum of four months before being considered noncompliant. Those women compliant for colposcopy received a repeat Pap smear and cervical biopsies. Women with confirmed dysplasia were advised to return for follow up treatment by laser, conization or hysterectomy. A repeat colposcopy was suggested if the previous colposcopy findings were unsatisfactory.

Findings of the record review revealed a 41 percent noncompliant rate for all women referred for the initial colposcopy exam. A difference in compliance was found among the long-distance referrals, but there was no statistical difference between the population of the community health center and of the larger gynecological center, revealing that transportation was not the primary cause of noncompliance. Those women completing the colposcopy exam were more likely to comply for follow-up treatment but a total of 32 percent failed to comply with treatment recommendations. Noncompliance was also shown not to be related to demographic variables such as race. This led to the study conclusion that once women have entered into follow-up care, they are more likely to complete treatment.

Funke and Nicholson (1993) studied factors influencing compliance for abnormal Pap smears by assessing for

relationships between health beliefs, locus of control and demographic variables and infection with the Human Papilloma Virus (HPV). Locus of control is a theory derived from the social learning theory which predicts that beliefs about one behavior can affect outcome (internal locus of control) or that factors beyond the person's control can affect outcome (external locus of control). The Health Belief Model (HBM) was used to assess for health behavior. The HBM predicts action by motivational factors: perceived susceptibility and severity of the disease, belief in the benefit of the health care action, and perceived barriers. The sample population was women 18 years of age and older that had been diagnosed with an abnormal Pap smear two to 18 months prior to their participation in the research. The final sample size was 272. This quantitative study found that the women described as noncompliant for any follow-up to their Pap smear had no significant relationships between compliance, the variables of locus of control and demographics such as education, income, age, partner status, ethnicity, number of children, diagnosis with HPV and symptomatic HPV infection. The study did not support Lane's (1983) for increased compliance if has symptoms of the disease. Risks for noncompliance were found to be significantly predicted by the statements "the uncertainty about my Pap test makes me nervous" (least likely correlation to noncompliance) and "I

have not been able to cope with my abnormal Pap test" as (significant in prediction of noncompliance). Limitations were cited as low response (13%) of the potential population (2,050) and 16-month time frame creating a potentially long span between diagnosis of the participant and research participation. Complete demographic data was also inaccessible due to concerns of confidentiality by the clinic administrator.

#### Pap Smear Research

Women's attitudes and feelings about having a Pap smear play an important role in understanding compliant behavior for both follow-up Pap smears and colposcopy exams. Although there are many information and opinion articles on Pap smears, few research studies were found regarding abnormal Pap smears and compliance to follow-up.

In 1988 an article was published on a survey by Elkind, Haran, Eardley and Spencer in Great Britain concerning reasons for non-attendance to a clinic for Pap smear screening. Some interesting findings were made. Women over age 50 were more apt to attend. Those that did not cited inconvenient appointment time and difficulty in getting to or finding the clinic. Using structured and open-ended questions, researchers conducted interviews with 56 women who did not attend over a six-month period. The most common concerns were: felt Pap smear not necessary for them because

of previous hysterectomy or lack of gynecologic problems, too old, did not like the test, found the test painful or embarrassing, feared the results, feared the clinic, forgot the appointment, and for some, a sense of fatalism. Motives for further testing included: obtaining peace of mind, the value of early detection, a desire to be safe, personal or family experience with cancer, or viewing testing as a "good thing."

A quantitative randomized controlled study was performed by Paskett, White, Carter, and Cher (1990) to test the effectiveness of an intervention (educational pamphlet) in increasing compliance for a repeat Pap smear recommended to women with an abnormal Pap smear result. One group received a notification letter about their abnormal results and recommendation for repeat Pap and an educational pamphlet. The second group received only the notification letter. The educational pamphlet was developed based on the Hierarchical Weighted Utility Model, which addresses issues responsible for compliance for recommended follow-up following a negative event. Those issues range from the value the woman places on her doctor's opinion about recommended follow-up to fears about cervical cancer including ten other issues. The compliance rate for the study population was 55 percent. A 12.9 percent increase in compliance between the groups (51.3 percent with the group

not receiving the intervention to 64.2 percent in the group that received the intervention) was found. The researchers felt their study was limited by the fact that the sample was comprised of women who were part of a special cervical cancer screening program and were self-selected to participate, therefore increasing the tendency to comply.

Paskett, Carter, Chu, and White (1990) developed a study using a dual qualitative/quantitative design to develop their test a "hierarchical weighted utility" model (used in Paskett, et al 1990 study previously discussed). This model was devised through open-ended interviews that identified issues women with abnormal Pap smears consider when deciding whether to obtain a follow-up Pap smear. The model was then evaluated through a second sample of women with abnormal Pap smears rating the importance they place on the issues in their decision to obtain the follow-up Pap smear. The participant sample was made up of ten compliant and eight noncompliant women. There were 12 issues in the model, ten relating to the Pap smear and two related to cervical cancer. The hierarchy ranged from the most important to least important reasons affecting the decision whether to have a repeat Pap smear. The results revealed 68 percent of the participants were accurately classified, 100 percent for compliers and 30 percent for noncompliance. The limitation of this research was stated as having subjects

recall issues related to a behavior that had already occurred.

In 1993 a survey was done by Bower to ascertain women's feelings about the Pap smear and their perception of its purpose, importance and accuracy. Data were collected through a random digit phone call (unfortunately the number called or the geographic area were not given). Most felt the Pap smear test was important in identifying cancer, but only 40 percent felt it was accurate. Ten percent said it could identify breast cancer and twenty percent had no idea the type of cancer detected. Surprisingly, sixty-four percent said their physicians did not inform them of a need for a Pap smear. Although limited, this survey indicates a need for education about Pap smears. The findings also point out the failure of health care providers to educate and promote Pap smears as an important step in women's health care.

#### Other Relevant Research

Other research on compliance issues was reviewed to assess for pertinent findings since compliance is such a universal problem in health care. There are many theories, models, and conceptual frameworks utilized in studies of it. Hill, Rassaby, and Gardner (1985) quantitatively studied three models that predict compliance for health care practices. The first was the Theory of Reasoned Action

(TRA) which predicts intention based on attitude (feelings about procedure) and subjective norm (influence of other's beliefs). Secondly, the Health Belief Model (previously discussed in Funke and Nicholson's, 1993 research). The third model was the Subjective Probability Model (SPM) which predicts intention based on the psychologic relevance of the event. The greater the relevance to the person the greater the intent for action.

One hundred and twenty-three volunteer females made up the study sample. No racial breakdown was provided but the median age was 34. The majority had completed at least four years of secondary school. A self-administered questionnaire was completed which included the components of the three models to assess for intention to "do breast self exam monthly from now on" and to "have a Pap test every two years." The TRA measurements were elicited through subject's choice among seven probability options from extremely unlikely to extremely likely, indicating the strength of belief about specific outcomes related to doing breast self-exam. The HBM measured barriers perceived by the subjects to do breast-self exam, and finally the SPM measured subjective probability related to breast-self exam and Pap test beliefs, such as how likely are you to perform breast-self exam if doing so would not increase worries for having breast cancer.



The findings supported the HBM and the TRA. Neither was superior, but both models predict intent for Pap testing more accurately than breast self-exam. The SPM also predicted intent for doing breast self-exam and having a Pap test. The most significant influences on intent for breast self-exam were: it causes false alarms, cancer could be curable, and provides reassurance about breast cancer. For intent to have Pap test, providing a sense of relief, embarrassing procedure, detection of cancer in early stage, creates worry about test results and physically unpleasant exam were the most significant influences cited. The barriers listed for breast self-exam included forgetfulness, laziness and not knowing how to do the exam. For the Pap test the most significant barrier cited was cost.

Levanthal, Singer and Jones (1965) conducted a quantitative study to see if follow-through with intent to obtain a tetanus shot was increased by providing a fear message about the disease and provision of a specific follow-up plan. Two groups of college students were studied. One group was given explicit information along with graphic pictures of tetanus infection and specific instructions on how to and where to get a "free" tetanus shot on campus. The second group was given information about tetanus without the graphics and scare tactics, and general information regarding location to obtain the shot.

Both groups were rated on intent to have the shot as well as their reaction to the tetanus information. Follow-up was done to see if the shots were obtained. The findings reveal a high rate of intent for the fear group to get the shot regardless of inoculation history. The other group showed an elevated rate of intent if they had not had a recent inoculation. Neither group showed a significant increased rate in obtaining the shot but those given specific plans were more apt to get the shot. To assess for intent purely as a motivator to obtain a tetanus shot, the researchers made a comparison between two sets of groups: those with a specific plan (without the fear tactic of the graphic picture and detailed serious effects of tetanus) and those without a plan. No one received a shot in those groups. The research conclusion was that fear alone is not enough to increase action but coupled with specific follow up instructions can increase follow through with intent.

Lane, 1983, utilized the health belief model to assess factors associated with compliance to provide knowledge of patient behavior and related implications for education in a quantitative research study. The sample studied were women in a high-risk group for breast cancer. Women attending the screening saw the American Cancer Society film on breast health; received a pamphlet on breast self-exam and obtained instructions by a health educator. An exam was then

performed including a Pap test and occult blood test for stools. Referrals for mammogram were done for those at high risk as well as referrals for other positive screenings. Data were reported on mammogram follow-up since receipt of the report reflected compliance. The overall referral rate was 44.6 percent. There was an increased compliance rate for women with reported symptoms of breast disease compared with asymptomatic women and women with positive physical findings on exam, regardless of age or personal or family history of breast cancer. As can be expected, the rate of compliance was greater for asymptomatic women if the mammogram was paid for by the project. The findings support the Health Belief Model's prediction of increased compliance if the woman had a perceived susceptibility to cancer and cost was not a barrier to action.

In studying various form of cancer prevention treatment, Burack and Liang (1987) assessed for procedure acceptance and completion related to various factors, such as patients' beliefs. This was a prospective quantitative descriptive study using a sample population of 221 from a primary care facility serving predominantly black elderly and low-socioeconomic patients. The participant's response to recommended cancer screening procedures such as Pap smear, pelvic exam, rectal exam, sigmoidoscopy or occult stool testing, mammography and breast exam was recorded as

acceptance, deferral or delay and refusal. Completion of the procedure was assessed through a chart and billing audit up to eight months after recommendation. Utilizing the four HBM components, interviews were also done by phone on a subgroup of 76 participants to assess for demographic information, knowledge of cancer and how to control it for those offered Pap smears, mammogram or stool occult blood test.

The results showed that of those offered any procedure 27 percent initially declined, but acceptance rated from 59 percent for sigmoidoscopy to 98 percent for breast exam. Subsequent completion of mammography was 61 percent, 50 percent for stool occult blood test and sigmoidoscopy and 69 percent for Pap smear. Initial acceptance was the largest factor for procedure completion.

The phone interviews testing the Health Belief Model's components found that less than one-third expressed concern for their future health or results of the check up. No participant believed she had a lifetime risk for breast cancer exceeding 10 percent. Ninety percent felt future illnesses could be prevented but 41 of the participants felt current available treatments were inadequate. The most common barrier to preventative procedures was a fear of finding something wrong. The conclusion was the Health

Belief model did not show a correlation with the acceptance of procedures.

A pilot study was performed to survey various health beliefs, knowledge about cancer and attitudes towards breast cancer by Fallowfield, Rodway and Baum (1990). The goal was to examine psychosocial factors which influence attendance or nonattendance for breast screening. The sample was drawn from 113 women attending a breast center in southeast London, England and nine women who failed to attend. The women attending the center were assessed for reasons for attending, the relationship with their physician, knowledge of breast cancer (prevalence, risks and causes) and perceived susceptibility, costs and benefits for screening. Those that did not attend were sent a questionnaire (which explains the small numbers in this group due to failure to complete and mail the questionnaire back). Data relevant to non-attendance were not provided since the response was so small.

A breakdown of responses was provided by the researcher. The most significant were that 48 percent of the attenders felt the mammogram caused some degree of pain, 84 percent cited a low prevalence of breast cancer, 49 percent indicated an elevated risk if they had family with disease, 40 percent felt oral contraceptives were a factor in development of breast cancer and 35 percent cited trauma

to the breast increased risk. Sixty-nine percent never or rarely did breast self-exam. One of the reasons for not performing breast self-exam was lack of confidence in performing correctly. Interestingly, 60 percent discussed with their family or friends their decision to attend the screening. Some were warned not to go for various reasons, the greatest being a painful exam.

In 1992 a quantitative study was done by Maiman, Hildreth, Cox and Greenland on compliance for follow up after receiving elevated cholesterol findings through a public screening program. Two groups of participants were studied, one with a history of elevated cholesterol and the other without a history. The participants found to have an elevation who were to be referred for follow-up were counseled randomly by either a lay counselor or a professional (RN). A coupon offer or reminder letter was used to encourage compliance. Five months after the screening and referral the participants were reviewed by phone to assess for compliance. Fifty-five percent of the participants overall complied with referral (54.8 percent of the group without a history of elevated cholesterol and 66 percent of the group with a history). For those without a history, both of the subgroups (those offered a coupon and those sent a reminder letter) had an elevated compliance rate compared to the control group receiving no follow-up.

There was no difference in compliance rate between type of counselor (lay or professional). There was a higher compliance rate with the coupon offer overall. For those noncompliant without history of elevated cholesterol a report of ability to care for self was cited as the reason and already in treatment cited for those with a history of elevated cholesterol. Less than 10 percent cited treatment cost as a barrier to follow-up.

Extending past research for an understanding of barriers and facilitators to preventative health care practices was attempted by Kurtz, Given, Given, and Kurtz (1993) through a quantitative examination of breast self-examination, mammography and clinical breast examination. The Health Belief Model and Bandura's Self Efficacy Theory were utilized to identify the barriers and facilitators to the health care measures. The Self Efficacy Theory postulates the belief that if people feel they have the ability to perform the health care behavior appropriately, then a prediction can be made for their ability to cope, their effort to perform the behavior and their persistence in performing that behavior. A sample of 1,607 women from various work sites in a city in Michigan with eighty-nine percent Caucasian, above 35 years of age with a high-school or greater education were studied. A questionnaire entitled the Health Care Practices Survey was designed containing two

segments. The first segment elicited demographic and personal history information such as preventative care practices. The second segment sought identified barriers and facilitators to breast cancer screening previously identified by past research (e.g., lack of knowledge, discomfort, fear, etc.). After revisions the instrument was finalized using a four-point Likert scale analyzing such things as demographic and personal history regarding mammogram, breast self-examination and clinical breast examination practices and beliefs.

The results revealed that 98 percent of the women surveyed knew how to perform breast self-exam, 65 percent had performed breast self-exam, and 59 percent were in compliance with American Cancer Society guidelines. Regarding mammography, 86 percent had at least one performed and 71 percent were in compliance with American Cancer Society guidelines. Ninety-seven percent have had a clinical breast exam and were 92 percent in compliance with American Cancer Society guidelines. Women frequently performing health care practices were more likely to comply with American Cancer Society's guidelines for breast self-exam, mammography and clinical breast exam. Discomfort and a lack of knowledge were most frequently cited as barriers to breast self-exam and mammography whereas discomfort and perceived importance were most frequent barriers to clinical



breast exam. Facilitators for all three practices were frequently cited as: a desire for control over health and perceived efficacy (ability to perform tests appropriately and consistently). Predictors for noncompliance were lack of knowledge, less perceived efficacy, less desire for control over health, and a high level of discomfort. The tool was successful in correctly predicting compliance or noncompliance in 65.4 percent for breast self-exam, 64.6 percent for mammography and 63.4 percent for clinical breast exam. The study sample was biased with a large percentage of Caucasian subjects who had some postsecondary education.

#### Conclusion

Often past research findings conflict, as was found in the review of literature for this study. Frequently it was found that a lack of knowledge served as a barrier to compliance for colposcopy and repeat Pap smears as well as other health care practices (Marteau, et al, 1990; Bower, 1993; and, Kurtz et al, 1993), but other research focusing on providing information about the tests and procedures showed no significant changes in subjects' anxiety level and compliance (Miller and Mangan, 1983; Barswick and Johnson, 1990; Lauver and Rubin, 1990; and, Lauver, Barswick and Rubin, 1990). Much was done to seek for common informational needs by women experiencing an abnormal Pap smear and referral for colposcopy or repeat Pap smear.

Lauver, Barswick and Rubin (1990) labeled subjects' attempts to seek causes for the abnormal Pap smear as "spontaneous causal Searching." They found no increased adaptation to having an abnormal Pap smear related to women's searching for causes of the negative event. Lauver and Rubin (1990) sought to show an increase in compliance for colposcopy if subjects received a specifically phrased message pointing out positive reasons for obtaining colposcopy and negative reasons for noncompliance, yet support for this type of message was found in their research.

In fact many of the theories developed to predict subjects' concerns regarding their health care and compliance are not supported. The Health Belief Model tested by Hill, Rassaby and Gardner (1985) and by Burack and Liang (1989) generated different conclusions. Hill supported the Health Belief model in their study whereas Burack and Liang did not show a correlation in predicting procedure acceptance.

The literature review sheds a great deal of light on the emotional and psychosocial response to negative events helping to understand the psychic trauma of receiving abnormal Pap smear results and repeat Pap smear or colposcopy recommendations. The most frequently cited responses were fear of cancer, fear of the procedure and concern about treatments. It was found by Kurtz et al

(1993), Paskett, et al (1990) and Elkine et al (1988) some reasons for noncompliance were fear of pain, fear of the results, fear of the procedure, a lack of knowledge and a lack of perceived importance. The most significant demographic characteristics of the noncompliant woman were young age and a limited history of health care problems experienced by the woman (Michielutte et al, 1985). Often the sample was biased towards a particular race, educational level and/or age, making generalizations difficult.

Many quantitative studies can be found on compliance but there are few qualitative studies. Research on noncompliant subjects was rarely found and those studies that did compare noncompliant with compliant patients were skewed towards the compliant (greater number of subjects in the compliant sample). More studies are needed specifically on the noncompliant patient for colposcopy. By combining an understanding of the emotional reactions to an abnormal Pap smear found in past research with more qualitative studies of noncompliant patients for colposcopy, an increase in compliance can be obtained through better counseling techniques. A humanistic approach (phenomenological research) will serve to elicit direct responses from the subjects rather than offering a choice of pre-determined alternatives providing a deeper understanding of all factors related to compliance.

## Chapter III

## Methodology

Study Design

Noncompliance for colposcopy is not only frustrating for the health care provider but poses a significant health risk for the woman with an abnormal Pap smear. Previous studies focused on the pathophysiological effects of abnormal Pap smears and on preconceived causes for noncompliance. The present study utilizes a phenomenological framework to study the emotions and feelings women have about their Pap smears and the forces that drive them to avoid compliance with recommended follow-up. Ideally the study's findings will lead to a better understanding of the noncompliant woman, resulting in improved communication by the health care provider and increased levels of compliance.

Qualitative research guided by phenomenology is usually unstructured and open to a free range of thoughts. The phenomenological method allows the researcher to focus on the subject's experience rather than on the subject as object (Munhall and Oiler, 1986). The goal of the method is to describe the total systematic structure of lived experience, including the meanings that these experiences had for the individuals who participate in them (Oiler, 1983, p. 50).

The present research was guided by Giorgi's phenomenological methodology, as described by Omery (1983, p. 52). This methodology involves six steps:

Step 1. The researcher obtains a naive description of phenomena by means of an interview with the subject.

Step 2. The researcher reads the entire description to get a sense of the whole.

Step 3. The researcher reads the description more slowly and identifies individual units. Some researchers call these units themes. The units or themes may be physical, psychological or emotional feelings the individuals experience which, combined, can explain the meaning of the experience or reasons for the behavior under investigation. "These units are discriminate, together making up the whole meaning of the experience" (Omery, 1983, p. 57).

Step 4. The researcher eliminates redundancies in the units, clarifying or elaborating the meanings of the remaining units by relating them to each other and to the whole. Through repeated examinations of the interviews, the researcher categorizes and codes similar units.

Step 5. The researcher reflects on the given units, and transforms the meaning from concrete language into the language or concepts of the science.

Step 6. The researcher then integrates and synthesizes the insights into a descriptive structure which is communicated to other researchers for confirmation and/or criticism. In the present study, similar units from each interview will be transcribed to reflect common concepts which are then categorized to reflect the barriers to colposcopy follow-up. The categories and codes reflecting the units from the interviews will be confirmed by the research participants, the thesis chairperson, and an experienced ethnographic researcher (a local professor of anthropology).

#### Selection of the Setting

Since it was found that past research primarily focused on poor black women, a variety of agencies were contacted to obtain a broader cross section of participants and include women of various ages and various cultural and socioeconomic backgrounds. Five private gynecology offices, four public health departments, one private non-profit organization and one college health center were contacted to obtain subjects.

All these agencies provide reproductive health services to women, some on a limited level. The private gynecology (GYN) offices offer a full range of gynecological care whereas the health departments, the non-profit organization and the college health center provide limited services. The health departments provide contraception services,

evaluation and treatment for sexually transmitted disease and colposcopically directed exams and treatment. The non-profit organizations offers contraceptives, sexually transmitted disease treatment, reproductive healthcare to women of all ages and colposcopy exams and treatment. The college health center is a primary care facility that offers exams and treatment for a variety of complaints for students of both sexes.

These agencies were located on the largely rural lower Eastern Shore of Maryland--Worcester, Wicomico, Somerset and Dorchester Counties. An urban site (Annapolis, selected because of its proximity and familiarity to the researcher) was included for comparison.

#### Selection of the Participants

The present research targeted English-speaking women with abnormal Pap smears who were referred for follow-up colposcopy but failed to keep their appointments. Excluded from the study were patients who, though initially noncompliant, demonstrated a potential for compliance through the fact of their calling to reschedule or to cancel follow-up appointments.

The initial pool of four agencies selected as resources proved inadequate as soon as problems in obtaining participants--including refusal of patients to participate, rare noncompliance problems in some settings, and the

absence of patients not originally referred by the researcher in her own practice setting--became evident. The pool was therefore widened to include seven private GYN offices, four county health departments, and five Planned Parenthood health centers. Of these, two private GYN offices, one health department, and one Planned Parenthood health center provided participants.

A person within the agency, using guidelines for the research (Appendix A) and the telephone strategy (Appendix B), would contact patients who failed to keep their initial colposcopy appointment to see if they would be interested in participating in the study. The researcher had intended to have the agency's contact person prepare the way for home interviews, but this plan proved unworkable. Some patients refused; others agreed to release their identities to the researcher but were either inaccessible by phone or, once contacted, showed no interest in a home interview. It was therefore decided that the agency person, when contacting patients to reschedule the colposcopy, would ask if they would agree to an interview in the office one hour prior to the exam, in exchange for which they would be paid \$10.00 whether the interview was completed or not.

In this way the researcher was able to conduct interviews with six women. (A pool of six study participants is not unduly small. Sampling in qualitative



research is usually small because the method generates a high volume of data, and once redundancy occurs the sampling is cut off.)

#### Characteristics of the Sample

The demographic questionnaire is shown in Appendix C. Table 1 represents the demographics of the six participants interviewed. Three were referred by private GYN offices in Wicomico County, two by the Wicomico County Health Department, and one by the Annapolis center of Planned Parenthood of Maryland. Of the three private GYN patients, two were notified of their abnormal Pap smears and colposcopy referral by mail; they delayed compliance for two months. The third private GYN patient (who had had colposcopy and laser treatment following an abnormal Pap smear seven years previously) was notified by phone by her family physician; she delayed for three months. Of the two participants from the Wicomico Health Department, one was notified by mail and delayed nine months before complying; the other was notified in person and delayed for two years. The one participant from the Annapolis Center of Planned Parenthood of Maryland was notified by mail; she delayed compliance for eight months. All patients received numerous follow-up letters and phone calls from the referring agency. The health department does home visits for their noncompliant patients in an attempt to get them in for colposcopy following up.

TABLE 1. Demographic Information

Interview	Age	Race	Marital Status	Number of Children	Age of Children	Level of Education	Employment Status	Total Household Income	Total No. in Household	Insurance	Religious Preference	Distance to Health Care Provider	Method of Transportation	Results of Pap Smear
Interview 1	28	White	Separated	1	12 years	12 years	Part-time	Less than \$10,000/yr.	2	Medical Assistance		Less than 15 miles	Personal car	Atypic
Interview 2	21	Black	Single	2	1 yr and 2 months old	Less than 12 years	Unemployed	Less than \$10,000/yr.	3	Medical Assistance		Less than 15 miles	Neighbor or Friend	Dysplasia
Interview 3	22	Black	Single	1	1 year	12 years	Unemployed	Less than \$10,000/yr.	3	Medical Assistance		Greater than 30 miles	Neighbor or Friend	Dysplasia
Interview 4	22	Black	Single	3	3 yrs, 1 yr., and 8 months old	12 years	Other	\$10,000-\$19,000/yr.	7	HMO	Hinduism	Less than 15 miles	Neighbor or Friend	Atypic
Interview 5	28	White	Single	0	-	12 years	Full-time	\$20,000-\$29,000/yr.	1	HMO		Less than 15 miles	Personal Car	Atypic
Interview 6	28	White	Single	0	-	1 to 2 years	Full-time	Less than \$10,000/yr.	3	None	None	Less than 15 miles	Personal Car	High

Noncompliant Behavior

One of the subjects received her GYN care at the health department but was referred out to a private GYN for colposcopy. Follow-up on noncompliance was done by the Health department for this patient.

It is important to note that those patients with atypical Pap smears previously experienced abnormal Paps ranging from atypia to repair cells. Only one participant was able to report her Pap results whereas the other results had to be obtained from the office nurse. One participant actually reported her Pap smear as being okay when in fact it showed dysplasia.

Three of the participants had to rely on a neighbor or friend for transportation; of these, one had to travel more than 30 miles to the health care provider. Three had personal cars and five out of six were fewer than 15 miles from their health care provider's office.

The ages ranged from 20 to 28 years with a mean of 23.5 years. Three were African American and three were Caucasian. All six were single (one was separated). Two had no children, one had three, one had two and two participants had one child. Ages of the children ranged from 12 years to 2 months. All but one participant had at least 12 years of education and one had up to two years of postsecondary education. Two worked full-time and two were unemployed. One worked part-time and the other was listed

as "other," signifying occasional work or job training. Two subjects had private medical insurance and three had medical assistance to pay for colposcopy. Only one had no insurance. She was receiving health care through a state grant.

#### Data Collection

Two pilot interviews were conducted to evaluate the effectiveness of the research questions in eliciting responses for the research data. The responses were found to be meaningful to the research, necessitating only a few changes in the original questions to guide the research to provide a better open-ended structure.

Data was collected solely by the researcher using an interview guide (Appendix D) and demographic questionnaire. Open-end questions were utilized to elicit further responses from the informants. The interviews were conducted in a private room at the participant's health care provider's office prior to her rescheduled colposcopy examination. After the first four interviews the questions were altered slightly to encourage further discussion of feelings about the abnormal Pap smear, how they were notified, and with whom they shared this information.

After being introduced by the agency nurse, the researcher began the interview by describing the purpose of the research, stressing the confidentiality of the findings

and the participant's right to end the interview at any time without reprisal by the agency or the researcher. It was explained that the interview would be tape recorded and that if the interview was ended by the subject at any time during the recording, the tape would be erased in her presence. If a participant chose not to be taped, the researcher would keep handwritten notes. A consent form (Appendix E) was then provided for signature once read and understood by the participant. A different consent was used with subjects from any of the local health departments as required by the Department of Health and Mental Hygiene Internal Review Board (Appendix F). All six subjects agreed to the taping and all six completed the interview.

Each tape recording was number coded to correspond to the number code on the demographic questionnaire and consent form. The interviews lasted 30 to 60 minutes, depending on the participant's responses. At each interview a rapport was developed enabling a free range of the subject's feelings and experiences to be expressed. There were frequent periods of silence to promote further comments by the subject. Verification of statements and rephrasing were also commonly used to elicit more responses.

Two of the participants wept during the interview and all six communicated some distress by wringing their hands or responding with laughter when questioned about their

abnormal Pap smear. At no point was medical intervention deemed necessary. Each participant was calm and relaxed at the end of the interview.

### Codes and Categories

Each interview was carefully transcribed verbatim and examined for persistent responses characterizing emotional, psychosocial or physical responses to the pap smear and colposcopy procedure. Codes were developed to reflect those responses and sorted on index cards with direct quotes from the interviews reflecting the code. After all the interviews were completed the codes were reviewed to look for similarities among reactions to the Pap smear and the recommended colposcopy and were grouped into categories. The categories reflect the unified experience with the codes describing the experience in more detail and in a more scientific language.

### Confirmation

Methods used to increase internal reliability in qualitative research include the use of low-inference descriptors, participant review of findings and peer examination. The first, low-inference descriptors, are "verbatim accounts of information provided by informants to the researcher" (Field and Morse, 1985, p. 120). Consistent questioning and typing the interviews verbatim for analysis as well as stringent coding and categorizing of the data

were utilized in this research as strategies to increase internal reliability of the study.

The second method to increase internal reliability described by Morse and Field is "participant review of findings" (1985, p. 130), in which the researcher reinterview participants in the study in an attempt to confirm the analysis of the data. Of the six participants in the present study, two were contacted for their assessment and opinion on the codes and categories developed to describe the experience of having an abnormal Pap smear and reasons for noncompliance. One participant has moved, two had no phone (disconnected) and one was contacted and agreed to the confirmation interview but hung up during the process. Calls were made immediately after the disconnection to see if it was accidental but she did not answer; her answering machine did. No further attempts were made as it was assumed this subject did not wish to continue the confirmation interview.

Telephone interviews were conducted with the two participants contacted for confirmation. The codes and categories were shared with them. Direct quotes reflecting the codes were provided and the participants were asked if she agreed with the description of the experience and whether the codes and categories captured their feelings.

Further discussion of the confirmation findings will be discussed in Chapter IV.

The third method described by Field and Morse to increase internal reliability is called "peer examination" (1985, p. 121). The data analysis in the present study was examined by the thesis committee chairperson, Dr. Edna Quinn, by colleague Tina Collins RN, MS, who has experience in qualitative research, and by Dr. Frank O'Connor, a professor at Lehigh University in Bethlehem, Pennsylvania. Dr. O'Connor is an anthropologist and has conducted and published ethnographic research. The data analysis and subsequent development of codes and categories was agreed upon by these three experts.

#### Ethical Constraints or Implications

There were no ethical constraints or implications in the study. Through the confidential method of obtaining subjects, non-invasive data collection and confidential interview setting, the subject was afforded the most comfortable and non-threatening environment possible for this study. No information from the interview was shared with care providers. The consent forms and demographic questionnaires were locked in the researcher's bank safety deposit box. Transcripts and tapes were kept locked in the researcher's home. Only the typist, researcher, and thesis committee members had access to the data. During the taping



only the subject's first name was used. No other identifying information was included.

The protocol for the research was approved by the Committee on Human Volunteers at Salisbury State University, the State of Maryland's Department of Health and Mental Hygiene's Institutional Review Board and the Planned Parenthood Federation of America (Appendix G, H, I, respectively). Approval was obtained prior to data collection. A second approval was obtained from the State of Maryland Institutional Review Board because of changes added since the original and the expiration of the original prior to completion of data collection (Appendix J).

## Chapter IV

## Data Analysis

Following Giorgi's method of data analysis, the interviews were transcribed verbatim then read and reread to develop codes and categories related to the emotional, physical and psychosocial barriers to follow-up compliance for colposcopy. According to Kraft and Webster (1988), "data management tasks are activities that prepare the data for analysis. Typically, these activities are reductionistic because they convert the data to smaller, more manageable units that are easily retrievable. In contrast, data analysis tasks facilitate extracting the meaning from a data set and are constructionistic because they focus on rebuilding and presenting the proposed data set in a thematic or conceptually relevant whole" (p. 196).

Codes and Categories

The process of intuition is used in the examination of data. To intuit is to look at an experience with an open mind, keeping previous experiences or knowledge from clouding the researcher's understanding of experience as the subject experienced it. The researcher must become totally absorbed by the experience, yet in order not to bias the conclusions not become a part of it (Oiler, 1981). Through a process of intuiting, then, the interviews were read and reread to analyze and develop an understanding of the

participant's reactions to their abnormal Pap smears and colposcopy. Similarities and themes evolved and were coded to reflect concepts relating to the experience of having an abnormal Pap smear and noncompliance for colposcopy. Subsequent interviews elicited more information to substantiate these similarities, allowing for comparisons of the experiences of different subjects. Twenty-one codes were developed to reflect the emotional, psychosocial and physical barriers to compliance for colposcopy.

Five code categories were then created, organizing the codes into groupings relevant to the research objectives: 1) perceptions of a woman's experience with abnormal Pap smears; 2) barriers experienced by noncompliant women for colposcopy; and 3) common causes of noncompliance for colposcopy in women with abnormal Pap smears. Table 2 lists the five categories with corresponding codes and the number of participants responding to that code. Interviewing continued, with ongoing analysis, until no new information was obtained.

Table 2  
Categories with Codes and Number  
of Responding Participants

		Number of Participants
<b>I. Fear</b>		
	Fear of Pain	4
	Fear of Body Image Changes	4
	Fear of Cancer/Death	5
	Fear of Procedure	2
	Fear of Unknown	3
	Infertility	2
	Nervousness	3
<b>II. Denial</b>		
	Avoidance/Procrastination	5
	Blocking/Suppression	4
	Fantasy/Wishful Thinking	5
	Mistrust of Results	2
<b>III. Social and Self-Influences</b>		
	Family	4 (-2, +2)
	Friends	2 (+2)
	Health Care Providers	5 (+3, -2)
	Acceptance/Taking Control	5 (+5)
	Self-Blame	2 (-2)
<b>IV. Lack of Knowledge</b>		
	Difficulty Understanding	5
	Terminology	5
	Lack of Information	5
<b>IV. Physical Obstacles</b>		
	Transportation	2
	Financial Impact	4

**Category I. Fears**

Fear was the most frequent reaction expressed by the participants. It was expressed regarding both the colposcopy procedure and the results of the exam. This fear took on many characteristics which needed to be coded separately for clarity of the emotion. The code statements reflect the individual features and nature of the emotion expressed by each participant during the interviews.

**Fear of Pain**

Fear of pain was expressed by four of the six participants. Some admitted that this fear prevented them from having the colposcopy exam. Comments reflecting fear of pain include the following:

- "I think it's going to hurt. She said I might have cramps. That's the only things that bothers me is the pain."

- "I don't like stuff like that. I don't like pain and I don't want it to hurt; and that's my big thing. No I don't like pain. I'm a wuss. That's a big part of it."

- "My girlfriend just went through it (hysterectomy from cancer of cervix). It's a lot of pain and she was laid up . . . out of work for a month and it's just a lot."

- "They hurt" (speaking of Pap smear)

- "She said it wasn't very painful. That's what I worried about."

- "She explained the procedure. She said it wouldn't hurt but I mean pain, that's not, I mean I can deal with the pain . . ."

**Fear of Body Image Changes**

Four of the participants expressed concern over potential changes in their bodies.

- "It bothers me, you know, knowing that there is something wrong with me. Just knowing that there is something wrong bothers me."

- "I don't want one" (addressing fear of hysterectomy)

- "I'm only 28 now. I've already had . . . 2 years I had half my womb removed and now this. The same again."

- "Now that I'm getting older I'm having a lot more problems. Not like when I was a kid but it's different. I never, I don't know, I didn't realize that there was so much to look after healthwise. It gets more complicated right along with life."

- "One minute you're healthy and the next minute they tell you something like this."

- "What's going on with your body, to make sure you're healthy and everything. Then when they tell you that you have cells changing and that means something could happen."

Fear of Cancer/Death

This is grouped together since each participant who mentioned cancer also spoke of death or alluded to it by her nonverbal response. Five of the six participants stated their fear of cancer or death from the results of the Pap smear and potential colposcopy results.

- "Fact that might happen. What kind of effect I might get. Cancer!"

- "I didn't know what that meant. All I know it was just related to cancer or something as being bad."

- "I have the idea that it's a detection that lets you know whether you have cancer."

- "I just know that I need to get it taken care of because it says it could cause like cancer of the cervix or something."

- "I was scared . . . cancer, which I don't want. I was afraid that I'd go in there and take the test and they'd tell me I had cancer . . ."

- "Only the cancer part scare me . . . That's the only time it scares me when they say cancer."

- "But now that I know that it is a big deal, that if you put it off you can get cancer and die from it."

- "I could get cancer and die if I don't take care of it . . ."

- "The main thing I thought about was cancer and I would die. That's all I could think about. It would spread and then it would get worse and I would die. That's all I thought about. I just knew it was something real serious."

**Fear of Procedure**

Two participants discussed their fear of the actual colposcopy procedure by relating it to their experiences in obtaining their Pap smears.

- "I can't stand to have a Pap smear done. Oh, I'm scared to death . . . like I said I can't even stand to have a Pap smear done so you know this is freaking me out."

- "When they take a Pap smear I was scared they might mess up or cause problems so they tell you not to move or something so they press down. It hurts."

**Fear of Unknown**

Three participants out of six expressed their fear of the unknown regarding the results of the colposcopy, their future health and if they can be helped.

- "Yeah, I wondered what they gonna find out and stuff . . . and what would going to happen to me."

- "Scared because I had problem in the past with laser cone. It was getting worse and worse and I don't know what's going to happen. It's just getting worse and worse."

- "I hope, I don't know" (speaking of possible help for whatever is found by colposcopy exam).



- ". . . but I guess the results of that today is really what I'm concerned about. What is wrong with me and what is going to have to be done."

- "I was thinking of the future like what are my kids going to do."

- "I know they say they really want to check this out but what can happen? Wonder what's going on."

### Infertility

Fear of infertility was expressed by two of the participants.

- "I guess it can lead to cancer; then you might not be able to have children."

- "... that also made me think cause later on down the road I do want children. Was she correct in telling me that? That it can make problems if you put it off?"

- "If I put it off, later on down the road or if I can't have them, well, if I'd taken that test I might be able to have them. That was some kind of impact on me, too."

### Nervousness

Three of the participants expressed nervousness over the colposcopy test results and their abnormal Pap smears. Statements reflecting this code include:

- "A little nervous cause I figured I'm young, I can't, I mean stuff like that . . . I mean it's scary at first, when they first tell you."

- "I'm just nervous. What are they going to tell me after I have this last test taken?"

- "I don't know how to describe it. I just felt like there was something wrong, you know, cause I've never gotten a bad Pap smear back before, so I just felt uncomfortable a little bit."

- "I was nervous I guess" (responding to how she felt during the counseling with the health care provider).

- "Yeah, like they tell me about or if the result come back, I get nervous about that."

- "No just being nervous of what they were going to tell me."

### Category II. Denial

This category demonstrates the various forms denial takes when women are confronted with news of their abnormal Pap smears. All the participants expressed denial in various context reflected in the codes. All the participants mentioned some form of denial as a reason for their noncompliance to colposcopy follow up.

**Avoidance/Procrastination**

Five out of six participants discussed putting off the colposcopy exam or avoiding the test. Statements illustrating this code includes:

- ". . . and then I was like, well, I can put it off."
- "I know I have an appointment but I know I can put it off."
- "I can put it off until another time and they'll give me another appointment."
- "If you make up your mind that you're not coming then you're just not. I just didn't come."
- "They wanted to set me up for a colposcopy down there but I just didn't go."
- "I didn't . . . anything could. I thought it wasn't a big deal."
- "I didn't know the extent it had so I just put it off, put it off, and put it off."
- "I was being stubborn and didn't want to do it."
- "that it really wasn't important enough for me to take time I guess."
- ". . . it slipped my mind at the time."
- "You know how you tell yourself, I ain't worried about . . . I don't care. I ain't going to that doctor."

- "I didn't want to do it so I didn't. I didn't want to know, I guess."

One participant missed her appointment and remembered it after several days had passed.

- "I thought it was another day and when I looked at my card it was already passed."

- "I just didn't want to go. I felt at the time, I felt like I didn't want to be bothered with it, you know."

#### Blocking/Suppression

Four of the participants refused to think about the abnormal Pap smear and colposcopy exam. Two said they stopped listening to the counselor after hearing they had an abnormal Pap smear.

- "They was explaining things but I wasn't paying them no mind."

- "I didn't think about it. I didn't want to think about it so I didn't."

- "I didn't want to think."

- "I wasn't paying them no mind . . . because nothing should be wrong with me."

- "Well at first I didn't pay it no mind. I just went home and paid it no mind."

- "Oh yeah, I was listening to them but it was just shooting everywhere."

- ". . . that's assuming the worst and it's probably not that way but I didn't want to hear it if it was."

- "I don't think about it. I don't want to do it."

- "I've got a million things on my mind." (When asked what kept her from understanding the counseling)

### Fantasy/Wishful Thinking

Some of the participants hoped to hear something different if they waited long enough and put off the colposcopy exam. Others hoped it would just go away.

- "For some miracle that it would go away without having to go through all the stuff that they told me I'd have to go through."

- "I hope it's nothing severe. I don't know."

- "I wish there was nothing wrong."

- "I was hoping it was okay."

- "Well, I can put it off. Just keep delaying it and maybe they'll tell me something different."

- "Just kept delaying it and maybe they'll tell me something different."

- "I didn't think it was as serious as it was, as it really is."

- "I just didn't think it was that important as they said it was."

- "I just always figured it would happen to someone that was older and I'm young."

One participant's response in questioning her about the possible effects of an abnormal Pap smear and what would happen if she did not follow up."

- "Nothing."

### Mistrust of Results

Two participants questioned the validity of their Pap smear results.

- "I went to Dr. \_\_\_\_\_ one time with my first pregnancy after I had it and he said there was nothing wrong.

- "Just so they're correct. I've heard alot of things about where they send the Pap smears off to the lab. They run them through so fast. They run them through so fast that they're not sure about it."

- "It was 20/20 or 48 Hours, I'm not sure . . . heard them talk about having so many of them they run through the lab and alot of times the results are inaccurate."

### Category III. Social and Self Influences

In two cases interactions with various people in the participants' lives had a negative influence on whether they took their Pap smear results seriously. More often, discussing the problem with a family member or significant

other was a positive influence. Also reflected was a sharing of the news with friends or family which was neither positive or negative. Eventually, compliance was initiated by self acceptance of the problem.

### Family

Four of the participants shared the results of their Pap smears with significant members of their family. Most often this member was their mother. In two cases the family member discouraged them from seeking care.

- "I showed my mom it (letter about Pap smear). She said nothing should be wrong with you and stuff like that and I just never called."

- "But my Grandmother, she always talks to me and tells me, don't worry about it. She's like, just wait. Don't get too upset, so maybe it hasn't hit me really."

On the other hand, family members could facilitate action.

- "I just need encouragement. My mom kept telling me that, "go ahead and have it done, you've got to think positive." And I started thinking well, it might not be so bad. I'll just go ahead and get it over with.

- "Recently the only person that I've really talked to is my cousin cause she's had everything removed because she had cancer." So she's one of the ones also told me to come do it."

- "I talked to my mom. She said for me to go get the colposcopy or whatever. She said that I should go. Don't put it off."

- "I just went in and I read it (letter about Pap smear) and I called and talked it over with my mom."

- "Yeah, me and my mom are really close."

- "I felt this was very personal and I don't talk to people about it except my mom. She's there for me."

#### Friends

Two participants talked with a close friend. In both cases the friend provided a positive influence, encouraging follow-up on the abnormal Pap smears. One discussed it with her boyfriend.

- "My girlfriend says they good up here and stuff."

- "Cause a friend of mine also told me she had the same thing done." She's had alot of problems and they told her that because she put it off so much it made her sterile." I just told her I was going in for a test and she told me that it was good that I wasn't putting it off anymore."

- ". . . plus my boyfriend told me I'd better have it done and I kind of listen to him somewhat."

#### Health Care Provider

Five of the participants expressed how the nurse or health care staff affected their willingness to keep the



colposcopy appointment and ability to communicate their concerns or questions. The following statement reflects the negative perceptions or interactions with the health care providers:

- "I guess I just thought I'd talk to her today when I came in." When asked if she preferred to speak to the nurse face to face she responded "yes."

- "They really didn't tell me much down there. They weren't as . . . they didn't explain it as well as they do here."

- "They really scared me down there. They tell you what to do and that's it. I really didn't know how serious it was."

- "I felt like they were looking down their noses at people; some of the employees, like, I don't know. They just kinda looking at you like you're a piece of trash walking in off the street. They really didn't explain. They didn't make you feel comfortable, you know."

The following statements represent positive perceptions of the health care provider:

- "They scared me more. The doctor scared me. That's one of the reasons . . ." (reason she stated she kept that day's colposcopy appointment).

- "She explains everything. I mean you don't have to worry or wonder about anything. If you don't have to

worry or wonder about anything. If you have any questions you can ask her and she can answer them for you."

- "I mean they do enough giving you the appointment and calling to let you know like a day or two ahead of time, that you have an appointment."

- "Here they explain things more."

- "I wouldn't ask my grandmother . . . and when something did come up wrong I didn't know how to ask anybody. They didn't really tell you and here they did."

- ". . . but now, you know, they sending the letters about I might get cancer or something like that. I try to go to the doctor."

- ". . . but now that you're sending me all these letters and all these notes and stuff, now I realize it was more important than what I thought."

- "Cause I got a letter, no, last week, and it was telling me or reminding me to."

- "When you started talking about this cancer stuff and I had this appointment so I realize I better go."

One participant offered advice for health care providers to encourage women to keep their colposcopy appointments.

- "Just tell them exactly what it is and if you scare someone enough sometimes that helps too. At least it did with me."

**Acceptance/Taking Control**

Since all participants were there for rescheduled colposcopy exams they were asked what influenced or encouraged them to keep the appointment rather than the others. Five of the six participants revealed an acceptance of their Pap smear results.

- "I started thinking well, it might not be so bad. I'll just go ahead and get it over with . . . I might as well face it. No need to keep putting it off and putting it off."

- "I can deal with the pain. I not worried about it. Just having it done . . . have it done, period."

- "I'm just waiting to go to Dr. \_\_\_\_\_ and see what's wrong and get it over with."

- "I'll be glad to just get it over with."

- "I've had a few done and they all came back abnormal, and I realized the problem wasn't going away. I was getting worse so I finally did something about it."

- "I almost backed out of it. I really did. I really didn't want to come here. I don't know. It's not going away. It needs taking care of and you know, I don't want to get any worse than it really is. But if I take care of it later. I would even be worse then so I might as well put up with it now."

- "Cause I want to get it taken care of. I don't want it to linger on and not be taken care of."

- "No, just get it over with. Getting whatever is wrong with me taken care of."

- "I knew I needed to come. I needed to really get serious. Take it seriously and come and find out exactly what's going on."

- "I said I was just going to come and it might be something serious and if I don't do this it might be something else and then I'll only have myself to blame cause I knew that I should have come."

- "I'm glad I came so I can go ahead and get it over with so I don't have to sit at home and wonder what's going on."

- "Make sure you have a Pap smear every six months" (speaking about future care).

### Self-Blame

Three participants blamed themselves or something they did as the cause for their abnormal Pap smears.

- "Just a mess up on my part" (excuse for not keeping appointments) "It was me, myself."

- "I just tense up so bad. I cause it myself (pain). I know that I tense up too much. I went 7 years without one (Pap) and when I got my first one since . . . so all this has been happening."

- "If I had gone as I should have, you know, then I probably would have had something more simpler."

- "They said maybe it was because I was pregnant (about first abnormal Pap smear). Maybe because I had my kids close together. I just wonder why this is happening to me. I think it's because my kids are so close together. As soon as I had one I was pregnant again and getting ready to have another and my body didn't have time to adjust."

- ". . . It was slightly abnormal but since I've put it off so much I'm in like the third stage . . . instead in the top layer it's going deeper and deeper."

#### **CATEGORY IV. Lack of Knowledge**

A lack of knowledge can impact on the patient's acceptance of the potential seriousness of having an abnormal Pap smear. All six participants expressed this in their interview. The three codes indicate the areas where counseling was insufficient for their understanding of the abnormal Pap smear and colposcopy procedure.

#### **Difficulty Understanding**

Five of the subjects commented on their difficulty in understanding the results of the Pap smear and what colposcopy entailed. Comments included the following:

- "Just that she explain to me it's more that they can see more with like a microscope, and that's about all I know."

- "I don't know." (When asked what her understanding is about an abnormal Pap smear and if it's not taken care of.)

- "I don't know." (When asked what her understanding is about an abnormal Pap smear and if it's not taken care of.)

- "I wasn't, I don't really know about the cells and all."

- "I don't know because I don't know what is wrong with me."

- "There are things that they told me that I'm just not understanding."

- When asked what she understood could happen to her her response was - "Nothing."

- "They explain. They explain." (When asked did she understand?) "Not really."

- "Oh, I guess they gonna check me for cancer or something."

- "I don't really know."

- "That it's a preventative measure against cancer, cervix cancer. That's all I really know about it."

- "Cause I didn't really know what treatment. All I knew it was just related to cancer or something."

Terminology

Five participants had difficulty understanding the terms used by their health care providers when counseled about the abnormal Pap smear results and colposcopy.

- "She just kind of explained to me that my Pap smear was, what's the word? I can't remember what the word was. It was something that came back negative, the cells or something."

- "I got a letter in the mail saying that it was, what do you call it? It was not clear but something was wrong with it, and they made me an appointment for . . . , to get a colposcopy or whatever it is called."

- "She just kind of explained to me that my Pap smear was, what's the word? I can't remember what the word was. It was something that had come back negative, the cells or something."

- It needed to be taken care of by, again what do you call it? Somebody higher than them, by a doctor or . . . "

- "I don't even know what colposcopy is."  
(when asked about the confusion of words used such as colposcopy one subject said: "yeah.")

- "I don't know. I mean they explained it but I don't know. I really don't." (In response to the word atypia.)

- "My mother, she was reading the paper and she was like what is this co---. I was trying to think of the word and she was asking me all the other words on the paper."

Lack of Information

Five of the six participants cited a lack of information or poor counseling provided by the health care provider who had notified them of their Pap smear results.

- "Well, I needed to talk to her about what kind of abnormal cell, what is really wrong, or; but I guess when they do the colposcopy or whatever that will show more."

- "She didn't tell me what's wrong with me or what's going to be the future. She didn't."

- "They just kept telling me it was an abnormal Pap."

- "No, they just told me that I have an abnormal Pap smear" (when asked if they told her this could lead to cancer if untreated).

- "No, I never heard of colposcopy until Monday."

- "They just said something about some cells were abnormal. That's all they said."

- "I don't know what to ask them cause I don't know what it is."

- "I just want to know what it is."

- "I think they could explain more so I would understand cause I ain't ask them hardly no questions."



- "Just be sure explain stuff better so we know what you all are talking about."

- "Just what's going to happen? How they're gonna take care of it? What's the procedure gonna be? Is it going to be awful and if not, is it going to be something simple or you know . . . I don't know."

- "That it's a preventative measure against cancer, cervix cancer. That all I really know about it."

#### **Category V. Physical Obstacles**

Other psychosocial and physical barriers to compliance are coded within this category. Obstacles can take on many facets. The two codes, although not mentioned as frequently, may indicate a major barrier to compliance for some women.

#### **Transportation**

Two participants stated that problems with transportation contributed to their failure to keep their colposcopy appointments.

- "but I didn't have no ride so I couldn't get, like, till I find a way up here."

- "Sometimes I don't have transportation."

**Financial**

This code covers financial concerns mentioned by four of the participants.

- "Sometimes I don't have a babysitter."
- "I only have Wednesday's off, so I have to get everything done on Wednesday."
- "My sister said I had a phone call but it was long-distance so I didn't call them back."
- "Well, financially I'd say."

**Confirmation**

Throughout the process of data collection and subsequent data analysis, confirmation of the research findings was done with input by the thesis chairperson and a colleague experienced in qualitative research. The final coding and categories developed through data analysis were a result of their input and agreement. Further assessment of data analysis was received from Dr. Frank O'Connor, a published ethnographic researcher and a professor of anthropology. Two confirming interviews resulted in verification of the code and category analysis. For one participant all the codes and categories reflected her experience with her abnormal Pap smear and noncompliance issues for colposcopy. The second participant re-interviewed agreed with the four categories but could substantiate only the codes she felt reflected her feelings.

She felt, however, that the other codes could reflect other's experience with an abnormal Pap smear and colposcopy referral.

Validation of the second confirming interview was reflected in the following statements:

**Fear of Cancer** - "I can go along with that."

**Fear of Unknown-** "I was afraid of what could go wrong."

- "When you're scared you're just not going to do it, no matter what."

**Denial - Blocking** - "After she told me again it just kind of hit me."

**Fantasy** - "Right, If I put it off long enough I wouldn't have to worry about it."

For the "social support" category the second interviewer felt her mother and taking control were the greatest influence for compliance for colposcopy. Self-blame was a barrier.

### Conclusion

Data analysis of the six interviews revealed five main categories reflecting the emotional, psychosocial and physical barriers for colposcopy following an abnormal Pap smear. The twenty-one codes provides detailed descriptions of the experiences under the categories. Findings and conclusions of the data analysis will be discussed in the

final chapter. Nursing implications, limitations, and recommendations for further research will also be included.

## Chapter V

## Summary

Discussion of Findings

The purpose of the present study was to describe, through a qualitative approach, the emotional, physical, and psychosocial barriers experienced by women who are noncompliant with recommended follow-up colposcopy procedures resulting from having an abnormal Pap smear. A description of the psychological impact upon a woman who learns she has an abnormal Pap smear was formulated, leading to some understanding of the woman's reason for noncompliance. The findings are not meant to be all-inclusive nor generalized to the general population. It is hoped, however, that health care providers can provide better counseling and encouragement to enhance compliance for colposcopy if they have a better understanding of the impact that having an abnormal Pap smear and subsequent colposcopy recommendations has on a woman.

The interview analysis resulted in five categories comprising the experience of having the abnormal Pap smear and factors influencing compliance for colposcopy. The emotional response of fear was the most poignant. The remaining four categories included: Denial, Social and Self Influences and Physical Obstacles. The findings of the study support past research. However, the resulting codes

and categories describing the experience are unique for this study methodology. The codes and their categories are not meant to be divided into the emotional, physical and psychosocial barriers, nor are they to be considered individually. Rather, findings are to be viewed as a whole to describe the entire experience of having an abnormal Pap smear for those subjects interviewed and the factors influencing their decision to not have the colposcopy exam.

### Fear

The emotional reaction of fear was described by each participant and was a reaction to both the Pap smear and the colposcopy procedure. This category included seven codes comprising the most frequently mentioned response by the subjects. Fear is described by Carpenito as "a state in which an individual or group experiences a feeling of physiologic or emotional disruption related to an identifiable source that is perceived as dangerous" (1992, p. 371). Fear for the subjects manifested itself in different ways.

Four of the participants expressed **fear of pain** in regard to the colposcopy procedure, future treatments, or past experience with Pap smears. Numerous studies of colposcopy follow-up support this code (Beresford and Gervaise, 1986; Marteau et al, 1990; Lauver and Rubin, 1991).

**Fear of body image changes** were also mentioned by four of the six participants. All expressed concern about abnormal changes occurring in what they felt was a normal healthy body. This can be defined as the state in which one experienced or is at risk of experiencing a disruption in the way one perceives one's body image according to Bersford and Gervaize (1986). They related it to their study on the emotional impact of colposcopy, and found that this emotion did not prevent follow-up for colposcopy but was cited as "the first realization" in young healthy women that their bodies might not be functioning perfect and under their control." (p. 85).

**Fear of cancer or death** was the most significant code for the fear category. Comments range from actual fear of cancer to fear of finding something wrong. Numerous studies support this finding and fear is quite often one of the major concerns expressed by clients with a serious illness (Beresford and Gervaize, 1986; Lauver and Rubin, 1991; Lerman, et al, 1991; Elkind et al, 1988; Paskett et al, 1990; and Burack and Liang, 1989).

**Fear of the procedure** was not the category mentioned most by the subjects. Most of the comments were directed towards a lack of understanding about the colposcopy exam and possible pain associated with it. Pain was felt with the Pap smear so the subject fear that the colposcopy would

be equally painful, if not more so. Beresford and Gervaise (1986), Marteau et al, (1990), and Paskett et al (1990), found fear of the colposcopy procedure to be one of the reactions in their studies on emotional responses and colposcopy compliance.

**Fear of the unknown** was mentioned by three of the subjects. One was concerned about the procedure results, the second worried about her future health care, and the third worried if the abnormal cervical changes could be stopped. Beresford and Gervaise (1986) found women scheduled for colposcopy frequently sought answers to these questions, but did not see an improvement in the emotional response to the procedure once the information was given. Bersevick and Lauver (1990, Marteau et al (1990), Lauver and Rubin (1991) and Lauver, Barsevick and Rubin (1990) found these same fears and questions related to colposcopy in their research.

**Fear of infertility** was expressed by only two of the subjects. One of the subjects was afraid she would become infertile as a result of her failure to follow-up for colposcopy. Studies reveal some women cite fear of infertility as an incentive to obtain follow-up for their abnormal Pap smear (Beresford and Gervaisi, 1986). Other studies include fear of alterations in sexual function, which include fear of an inability to function as a female,



which comprise all facets of femininity (Paskett et al, 1990). This is found in the Hierarchical Weighted Utility Model developed by Paskett to predict compliance behavior with abnormal Pap smears.

**Nervousness** was an emotion expressed by three of the subjects. "I felt nervous" or "I was nervous about that" expressed their response upon hearing the news of the abnormal Pap smear to how they felt knowing they were about to have the colposcopy exam. Lauver and Rubin (1991) found nervousness expressed at the subjects' colposcopy visit regarding the seriousness or implications of the findings. Funke and Nicholson (1993) found that nervousness expressed by subjects had no negative effect on compliance.

### Denial

The category of denial (defined as "blocking painful or anxiety-producing aspects of reality out of consciousness" [Kozier, Erb, & Olivieri, 1991, p. 802]) was found to be significant as a coping mechanism in response to the fear of the subject's abnormal Pap smear results. This defense mechanism can be either constructive or destructive in coping with health issues. Miller and Mangan (1983) found that patients who avoided information about the colposcopy procedure adapted better psychologically than those who sought information. Ineffective denial is defined by Carpenito (1992) as "the state in which an individual

minimizes or disavows symptoms or a situation to the detriment of his health (p. 283). In the present study, denial was maladaptive for colposcopy compliance.

**Avoidance/procrastination** was one of the most frequently cited codes for the denial category. procrastination occurred for three subjects when they stated they kept "putting it off." This is a form of avoidance. White, Richter and Fry (1992) and Bombardier, D'Amico and Jordan (1990) found avoidance to be one of the coping mechanisms experienced by clients with chronic illnesses. Both their studies found this to be less successful for adaptation to an abnormal Pap smear.

**Blocking and Suppression** are terms related to the psychological response experienced by clients or family when confronted by distressing news. The person tunes out all other information in his or her attempt to cope with the psycho-physiological trauma. Kozier, Erb, and Olivieri (1991) refer to "suppression" as "consciously and willfully putting a thought or feeling out of mind" (p. 801). Taber's Cyclopedic Medical Dictionary (1973) defines blocking as "a sudden, unaccountable stoppage of speech or thought, may be due to a conflict or painful thought" (p. B-38). Four of the subjects either heard little of the counseling after receiving their Pap smear results because they were focused on the emotional response to the test results or they

purposely blocked everything out because they didn't want to hear it. Fallowfield, Rodway and Baum (1990) and Miller and Mangan (1983) supported this concept in their research.

**Fantasy/Wishful Thinking** is a form of denial often used as a defense mechanism during stressful events. Five of the participants experienced this response in two different ways: hoping that if enough time went by the problem would go away, or hoping to be told something different - for example, that the Pap smear results were normal. Felton and Ravenson (1984) described wish-fulfilling fantasy as "wishing for the illness to be over with or for life to be different and escaping into pleasant fantasies" (p. 346). White, Richter and Fry (1992), Felton and Reverson (1984), and Bombardier, D'Amico and Jordan (1990) found fantasy or wishful thinking a maladaptive coping response to chronic illness. This code was not addressed by the research reviewed on colposcopy and Pap smears.

**Mistrust of results** was a code cited by two of the participants. It is frequently mentioned in the literature as a response to the abnormal Pap smear results. Bower (1993) found that only 40 percent of the women he surveyed believed the Pap smear was accurate. Paskett et al (1990) listed mistrust as part of the Hierarchical Weighted Utility Model, developed to explain and predict compliance behavior for abnormal Pap smears. Burack and Liang (1987) in their

study of acceptance and completion for recommended procedures found that a significant number of women who had not followed up on a recommended health care procedure believed the results were or could be inaccurate.

#### Social and Self Influences

**Social support** theory predicts a positive outcome or acceptance to illness when the patient has emotional support from friends, family and/or the health care staff. The present study's findings indicate that family, friends and health care providers can have either a negative or a positive effect on a patient's compliance with recommended colposcopy follow-up. The three codes **family, friends and health care provider** were supported by the research of Paskett et al (1990), Fallowfield, Rodway and Baum (1990), and Hill, Gardner and Rassaby (1985). White, Richter and Fry (1992) also found that social support was important in adapting to chronic illnesses, further supporting this concept. **Self influence** is a reflection of adapting to illness and taking self control.

**Acceptance/Taking Control** are codes comprising a historical process. Five of the six participants eventually complied with the colposcopy recommendations because they had worked through their fears enough to "want to know what was going on." Support for this code can be found in most health care literature. Kurtz et al (1993) found that women

who were compliant for preventative health care practices cited a desire for control over their health as a facilitator for compliance. Hill, Gardner and Rassaby (1985) found that Pap smear compliance increased for those women who believed that performing health practices provides a sense of relief.

**Self-blame** was cited by two participants as a cause of their abnormal Pap smears. Though not a barrier to compliance, self-blame played a significant role in their fears. Lauver, Barsevick and Rubin (1990) and Lauver and Rubin (1990) found that women seeking answers to the cause of their abnormal Pap smear frequently asked questions relating to what they might have done to cause the abnormality. Interestingly, Lauver and Rubin (1990) found that subjects frequently blamed their partner or healthcare practitioner.

#### **Lack of Knowledge**

All six participants commented on their difficulty understanding either the Pap smear results or the colposcopy procedure, for a variety of reasons ranging from a lack of counseling to lack of knowledge about medical terminology. Gordon (1993) defined lack of knowledge or knowledge deficit as an "inability to state or explain information or demonstrate a required skill related to disease management procedures, practices, and/or self-care-health management"

(p. 239). She continues to offer some defining characteristics such as: "verbalizations indicate less than adequate recall of information or inadequate understanding, misinterpretation, or misconception and inaccurate follow-through of previous instruction" (p. 239). Kurtz et al (1993) studied the barriers and facilitators to compliance for health screening as related to the Health Belief Model and found a lack of knowledge to be one of the greatest barriers to compliance.

Because most of the participants did not understand what the Pap smears meant or what colposcopy was, they had difficulty in understanding the potential seriousness of the problem. Barswick and Lauver (1990), Marteau et al (1990) and Lauver and Rubin (1991) found that women sought answers to the meaning of the Pap smear and what happens during colposcopy. Bower (1993) found that a significant percentage of his study sample cited a lack of understanding about the Pap test when assessed for their perception of its importance and purpose, also reflecting a lack of information.

**Terminology** used in counseling was also cited by most participants as a barrier to understanding their abnormal Pap smear results and the colposcopy procedure. Colposcopy was a term they had never heard before and could not even pronounce, let alone describe what it means. A study by

Byrne and Edeani (1983) on use of medical terminology with hospital patients showed that the patients had difficulty understanding terms and felt this hindered their compliance in their health regimen. Spees (1991) replicated Byrne and Edesni's (1984) study in her investigation of patient's knowledge of common medical terms. She also found the respondents had difficulty in understanding medical terminology.

A lack of information reflects not only the amount and quality of counseling but also reveals differences in the method by which the information is relayed to the patient. Most of the subjects were notified of their abnormal Pap smear by mail. Further counseling was frequently done either by phone or in person. Five of the six participants in the present study reported a lack of information provided by the health care provider, fostering their difficulty in understanding. Although not all patients need a lot of information or even desire it, Miller and Mangan (1983) found a difference in stress level between those needing more information and receiving it and those needing information and not receiving it. Barswick and Johnson (1990) found those participants showing a preference for involvement in their health care also sought more information. Barswick and Lauver (1990) and Lauver and Rubin (1991) found certain common questions were asked about

the colposcopy procedure, results and what the abnormal Pap smear means in the majority of their study participants. They concluded that by increasing an awareness of the type of information needed more effective counseling could be developed to allay patients' fears. Unfortunately, providing more information to subjects did not significantly increase compliance.

### Physical Obstacles

The category of physical obstacles comprised the most direct causes of noncompliance for the participants. Numerous variables have been listed as possible obstacles to health care from the concrete obstacles, such as cost, to the more abstract obstacles, such as in the emotions experienced with negative events.

Transportation is frequently considered a barrier to compliance, but is cited by only two of the participants as a reason for noncompliance. Laedtke and Dignan (1992) did not find long distance from the health care provider to be a significant cause for noncompliance, whereas Elkine, et al (1988) did.

Cost or financial impact was cited by four of the participants as factors for noncompliance. This was not related to the cost of the procedure since those that did not have insurance were receiving subsidized health care through public assistance or government grants. The



financial impact for them was time off from work (wouldn't get paid), cost of child care and cost of long distance calls (to return call to health care provider after contacted, but not reached regarding Pap smear results). Lane (1983) found when mammograms were paid for by the agency, compliance increased for those patients. Paskett et al (1990) found that costs were frequently cited for noncompliance but were not a significant barrier. Hill, Gardner and Rassaby (1985) found the cost of the Pap test to be a significant factor for noncompliance in their study.

### Conclusion

The present study attempts to describe the emotional, psychosocial and physical barriers to colposcopy compliance. Through a qualitative approach, the total experience of women with abnormal Pap smears was studied in an attempt to understand their response to the Pap smear and their subsequent noncompliance. The five categories -- **Fear, Denial, Social and Self Influences, and Physical Obstacles** - provide health care providers with concepts to describe the experience. The twenty-one codes serve to describe the experience in more detail.

The research findings suggest the emotional responses of **fear** and **denial** to be a common response by women when advised they have an abnormal Pap smear. The third category, **Social and Self Influences** indicates other

psychosocial barriers and in some cases, facilitators to compliance for colposcopy. Category four, **Lack of Knowledge**, supports the literature on patient's understanding of the problem and reveals a potential barrier to the realization of the seriousness of the abnormal Pap smear and the importance of compliance for colposcopy. Category five, **Physical Obstacles**, supports existing research for noncompliance. The experience of having an abnormal Pap smear generate both emotional and physical responses in the woman. The categories attempt to describe what those responses are, with the fifth category, physical obstacles, being more easily addressed by health care workers.

The limitations of the present research include the small sample, although an attempt was made to get more participants. Few were willing to participate in the study. The objective, to include a cross section of women without bias to race, age or socioeconomic status, was also limited due to the small sample. A consent to look at the subject's charts would have been helpful in assessing for methods of contact and the entire Pap smear results. Interviewing prior to the colposcopy exam may have heightened the participant's fear response and does not address the truly noncompliant patient (one who would never come to the office for colposcopy). Confirmation was done several weeks after

the participants had their colposcopy exam, which may have limited their responses to the codes and categories due to their altered emotional state since the procedure was over and they were aware of the results. This may have made reflections on past emotional responses difficult. In addition, confirmation with two out of six participants reduces the credibility of the findings.

### Nursing Implications

Past research and the present study's findings suggest frequent causes for noncompliance with health care. The woman with an abnormal Pap smear experiences emotions that may paralyze her and prevent her from taking the steps necessary for follow-up. The nurse is most often the one responsible for notifying the female client about her Pap smear results. In the case of an abnormality this notification becomes thwarted with counseling demands, appointment scheduling, and dealing with the emotional impact on the client. A knowledge of what that emotional impact is and how it can influence a patient to complete the recommended follow-up is imperative for successful counseling by the nurse.

The five categories and 21 codes describing the emotional, psychosocial and physical barriers to compliance for colposcopy follow-up may serve to guide the nurse in her counseling and follow-up for those women with an abnormal

Pap smear with recommended colposcopy. Although studies have shown common responses to the Pap smear, each person is an individual and may need different types of information not only to comprehend the repercussions of an abnormal Pap smear, but to accept it emotionally. By using the categories and what they imply, health-care providers can counsel their female clients more effectively.

Fear as a category elicited seven different responses revealing multiple reactions to the abnormal Pap smear and the colposcopy exam. Not all of the subjects experienced the same fears. Fear of pain, body image changes, and fear of cancer or death were most commonly expressed by subjects, revealing different aspects of fear. Fear of the procedure and fear of the unknown point out definite areas counseling can concentrate on to expand the knowledge for the client and hopefully reduce the fear. A fear of infertility or loss of reproductivity can frequently be allayed by proper counseling, but in some cases an abnormal Pap smear may be a risk and one that should be carefully explored with the client by the nurse. Fear is a powerful emotion. Nurses must be aware of this response by clients especially when confronted by a potentially life-threatening event. This fear must be addressed and the level of nervousness decreased to help enable the client to hear the information provided and to respond appropriately to follow-up.

Denial also elicited four different types of response. Counseling directed at fear or denial alone will not be effective for all clients. The nurse should explore with the client her individual needs. Be aware that, once they've heard the news of the abnormal Pap, everything else said after that is lost to some clients because they have focused their attention on the abnormal Pap smear and do not hear anything else. This client will need to be given time to absorb the news before further counseling can be provided. It may be helpful to show the Pap smear results to the client and discuss the accuracy of the test results.

It has been shown that others influence health care decisions, whether they be the health care staff, family or friends. The nurse is responsible for providing a non-judgmental attitude when dealing with clients. As was shown by this study, the health care staff can serve as a positive or a negative influence in follow up. In addition it may be helpful to include the one that provides the support to the client by inviting the client to ask that person to come in for the counseling.

The barriers to follow-up take on many forms. A lack of knowledge was the most significant for this study and points out to nurses the importance of the teaching. Simpler terminology, diagrams and reading materials should be used to educate the client about her Pap smear and the

colposcopy procedure. This study also points out the client's need for information on Pap smears prior to receiving the result. By understanding the procedure and what the pap smear is testing for, clients will be more prepared for the results--especially if they are atypia or dysplasia--since she has been told that those results indicate a precancerous change, not cancer. Along with the explanation the client also needs to know follow-up procedures are available to prevent cancer from developing.

Transportation and financial problems serve as major barriers to follow-up. The nurse should discuss these with the patient and offer suggestions to alleviate those barriers. If the problem is transportation, the nurse can look for a treatment location closer to the client or offer more flexible hours, such as evening or weekends, to get the client in for colposcopy. Child care is also a frequent financial burden. The women often cannot afford a sitter or cannot arrange for a family member or friend to watch the children. Again, more flexible scheduling may help.

As has been shown by the present study, reactions to abnormal Pap smears and colposcopy follow-up serve as barriers to obtaining follow-up. Responses to the Pap smear may take on various forms according to the individual. Nurses in their holistic approach to care need to be aware of research findings and apply them to their health care

practices. Nurses must provide individualized counseling, considering the needs of their clients, and must strive to assist clients in meeting their needs, to allow for positive responses to abnormal Pap smear follow-up and improved outcomes. Persistence in counseling and follow-up for noncompliant patients is frequently necessary to break through the barriers for compliance.

#### Recommendations for Future Research

More research is needed that utilize the qualitative design to study the holistic experience of having an abnormal Pap smear and colposcopy referral. Qualitative methods and research will provide deeper understanding of the experience and reasons for noncompliance. This research left unanswered questions which can be further studied. It was found that all of the private physician's offices contacted for study subjects had rare problems with noncompliance. Further research is needed to evaluate why there is better compliance in private offices than in public health care facilities. The notification and counseling techniques should be reviewed and possible differences in demographics for that facility's patient population should be compared. Do the private offices draw more educated clients or does ability to pay correlate with compliance rates? Does payment for services boost compliance?

It was also found that the truly noncompliant client was not part of this study since those persistently noncompliant refused to participate, nor is there data available on the continuously noncompliant client. Research into this population is much needed to break through those barriers and improve compliance, thus improving health care outcomes.

This research must be viewed as preliminary, since so few participants were involved. Redundancy began to occur early in the study, reflecting a potential bias in the study sample. Further research is needed to explore this concept and to add more data so saturation can be made to increase the credibility of the data.

### Summary

Noncompliance with health care recommendations will be a problem as long as there are health care practices and treatment regimens to follow. An awareness of reasons for noncompliance is crucial in any attempt to develop plans to increase client compliance. Overcoming physical barriers such as cost and transportation will not encourage compliance in all cases. Nursing, as a profession, must consider all factors affecting compliance. Knowledge of emotional responses for the individual client as well as psychosocial factors influencing his or her decision to follow through on recommended health care practices will



serve as a foundation to improving counseling techniques and eliminating barriers to compliance.

## References

- American Cancer Society. Cancer facts and figures 1992. Atlanta, GA.: American Cancer Society, 1994.
- Barsevick, A. & Johnson, J. (1990). Nursing Research: A Qualitative Perspective. Norwalk, Connecticut: Appleton, Century, Crofts.
- Barsevick, A. & Lauver, D. (1990). Women's informational needs about colposcopy. Image: Journal of Nursing Scholarship, 22 (1), 23-26.
- Beresford, J. & Gervaize, P. (1986). The emotional impact of abnormal Pap smears on patients referred for colposcopy. Colposcopy & Gynecologic Laser Surgery, 2 (2), 83-387.
- Bombardier, C., D'Amico, C., & Jordan, J. (1990). The relationship of appraisal and coping to chronic illness adjustment. Behavioral Research and Therapy, 28 (4), 297-304.
- Bower, M. (1993). Women's knowledge, attitudes, and behavior toward Papanicolaou testing. The Female Patient, 18 (3), 16-21.
- Burack, R. & Liang, 77J. (1987). The early detection of cancer in the primary-care setting: factors associated with the acceptance and completion of recommended procedures. Preventive Medicine, 16, 739-751.

- Byrne, T. & Edeani, D. (1984). Knowledge of medical terminology among hospital patients. Nursing Research, 33, (3), 178-181.
- Carpenito, L. (1992). Nursing Diagnosis: An Application to Clinical Practice (4th ed.). Philadelphia: J. B. Lippincott Company.
- Chatelain, R., Schunck, T., Schindler, E., Schindler, A., & Böcking, A. (1989). Diagnosis of prospective malignancy in Koilocytic dysplasias of the cervix with DWA cytometry. The Journal of Reproductive Medicine for the Obstetrician and Gynecologist, 34(8), 505-510.
- Elkind, A., Haran, D., Eardley, A., & Spencer, B. (1988). Reasons for non-attendance for computer-managed cervical screening: pilot interviews. Social Science Medicine, 27 (6), 651-660.
- Fallowfield, L., Fodway, A., & Baum, M. (1990). What are the psychological factors influencing attendance, non-attendance and re-attendance at a breast screening centre? Journal of the Royal Society of Medicine, 83(9), 547-55.
- Felton, B. & Revenson, T. (1984). Coping with chronic illness: a study of illness controllability and the influence of coping strategies on psychological adjustment. Journal of Consulting and Clinical Psychology, 52(3), 343-353.

- Funke, B. & Nicholson, M. (1993). Factors affecting patient compliance among women with abnormal Pap smears. Patient Education and Counseling, 20, 5-15.
- Giordano, D. & Dersek, D. (1988). Changing Health Behavior. Scottsdale, Arizona: Gorsuch Scarisbrick Publishers.
- Giuntoli, R., Atkinson, B., Ernst, C., Rubin, M., & Egan, V. (1987). Atkinson's Correlative Atlas of Coloscopy, Cytology, and Histopathology. Philadelphia: J. B. Lippincott Company.
- Gordon, M. (1993). Manual of Nursing Diagnosis, 1993-1994. St. Louis: Mosby-Year Book, Inc.
- Hill, D., Gardner, G., & Rassaby, J. (1985). Factors predisposing women to take precautions against breast and cervix cancer. Journal of Applied Social Psychology, 15(1), 59-79.
- Howard, J. (1987). 'Avoidable mortality' from cervical cancer: exploring the concept. Social Science Medicine, 24 (6), 507-514.
- Knaack, P. (1984). Phenomenological research. Western Journal of Nursing Research, 6(1), 107-114.
- Knafl, K. & Webster, D. (1988). Managing and analyzing qualitative data: a description of tasks, techniques, and materials. Western Journal of Nursing Research, 10(2), 195-218.

- Koopmanschap, M., Van Oortmarssen, G., van Agt, H.,  
VanBallegooijen, M., Habbema, J. & Lubbe, K. (1990).  
Cervical-cancer screening: attendance and cost-  
effectiveness. International Journal of Cancer, 45, 410-  
415.
- Koss, L. (1989). The Papanicolaou test for cervical cancer  
detection. A triumph and a tragedy. JAMA, 262 (5), 737-  
743.
- Kozier, B., Erb, G., & Olivieri, R. (1991).  
Fundamentals of Nursing: Concepts, process and practice  
(4th ed.) Redwood City, California: Addison-Wesley  
Publishing Company.
- Kurtz, M., Given, B., Given, C., & Kurtz, J. (1993).  
Relationships of barriers and facilitators to breast  
self-examination, mammography, and clinical breast  
examination in a worksite population. Cancer Nursing,  
16(4), 251-259.
- Lane, D. (1983). Compliance with referrals from a cancer-  
screening project. The Journal of Family Practice, 17  
(5), 811-817.
- Laedtke, T. & Dignan, M. (1992). Compliance with therapy  
for cervical dysplasia among women of low socioeconomic  
status. Southern Medical Journal, 85 (1), 5-8.

- Lauver, D., Barsevick, A., & Rubin, M. (1990). Spontaneous causal searching and adjustment to abnormal Papanicolaou test results. Nursing Research, 39 (5), 305-308.
- Lauver, D. & Rubin, M. (1990). Women's concerns about abnormal Papanicolaou test results. JOGNN, 20 (2), 154-159.
- Lauver, D. & Rubin, M. (1990). Message framing, dispositional optimism, and follow-up for abnormal Papanicolaou tests. Research in Nursing and Health, 13, 199-207.
- Lerman, C., Miller, S., Scarborough, R., Hanjani, P., Nolte, S. I. & Smith, D. (1991). Adverse psychologic consequences of positive cytologic cervical screening. American Journal of Obstetrics and Gynecology, 165, 658-662.
- Lerman, C., Riner, B. & Engstrom, P. (1991). Cancer-risk notification: psychosocial and ethical implications. Journal of Clinical Oncology, 9 (7), 1275-1282.
- Levanthal, H., Singer, R. & Jones, S. (1965). Effects of fear and specificity of recommendation upon attitudes and behavior. Journal of Personality and Social Psychology, 7(1), 20-29.

- Maiman, L., Hildreth, N., Cox, C., & Greenland, P. (1992). Improving referral compliance after public cholesterol screening. American Journal of Public Health, 82 (6), 804-809.
- Marteau, T., Walker, P., Giles, J., & Small, M. (1990). Anxieties in women undergoing colposcopy. British Journal of Obstetrics and Gynecology, 97, 859-861.
- Michielutte, R., Diseker, R., Young, L. & May, J. (1985). Noncompliance in screening follow-up among family planning clinic patients with cervical dysplasia. Preventive Medicine, 14, 248-258.
- Miller, S. & Mangan, C. (1983). Interacting effects of information and coping style in adapting to gynecologic stress: should the doctor tell all? Journal of Personality and Social Psychology, 45 (1), 223-236.
- Morse, P., & Morse, J. (1985). Nursing Research: The Application of Qualitative Approaches. Rockville, Maryland: Aspen Publishers, Inc.
- Munhall, P. & Oiler, C. (1986). Nursing Research: A Qualitative Perspective. Norwalk, Connecticut: Appleton, Century, Crofts.
- Oiler C. (1982). The phenomenological approach in nursing research. Nursing Research, 31 (3), 178-181.
- Omery, A. (1983). Phenomenology: a method for nursing research. Advances in Nursing Science, 5, (2) 49-63.

- Paskett, E., Carter, W., Chu, J. & White, E. (1990).  
Compliance behavior in women with abnormal pap smears:  
Developing and testing a model. Medical Care, 28 (7),  
643-656.
- Paskett, E., White, E., Carter, W., & Chu, J. (1990).  
Improving follow-up after an abnormal pap smear: A  
randomized controlled trial. Preventive Medicine, 19,  
630-641.
- Polit, D. & Hungler, B. (1991). Nursing Research Principles  
and Methods (4th ed.). Philadelphia: J. B. Lippincott  
Company.
- Porter, E. (1989). The qualitative-quantitative dualism.  
Image: Journal of Nursing Scholarship, 21 (2), 98-102.
- Reid, R. & Greenberg, M. (1990). Classifying HPV-  
associated lesions. The Female Patient, 15, 45-56.
- Spees, C. (1991). Knowledge of medical terminology among  
clients and families. Image, 23, (4), 225-229.
- Stafi, A. (1990). Cervicography in cervical cancer  
detection. Post Graduate Obstetrics & Gynecology, 10  
(3), 1-6.
- Thomas, C. (1973). Taber's Cyclopedic Medical Dictionary  
(12th ed.). Philadelphia: F. A. Davis Company.
- White, N., Richter, J., & Fry, C. (1992). Coping, social  
support, and adaptation to chronic illness. Western  
Journal of Nursing Research, 14 (2), 211-224.



Young, S. (1986). Strategies for improving compliance.

Topics in Clinical Nursing, 7 (4), 31-38.

**APPENDIX A**

Abstract for Agency Contact

Noncompliant Behavior for Colposcopy Exam  
in Women with Abnormal Pap Results

Purpose —

Noncompliance for colposcopy is not only frustrating and costly for the health care providers but also places the client at a greater risk when coloscopy is postponed. This research proposes to study the noncompliant behavior by interviewing clients with abnormal Pap smears who have failed to keep their coloscopy appointment. By developing a better understanding of the client's behavior, the health care provider can implement changes to meet the needs of the client. This will increase the compliance rate, reduce costs for the facility, and reduce the risk of cancer for the client.

Methodology —

Initial contact will be made by the health care facility staff person. Clients with abnormal Pap smears who do not show up for their colposcopy exam will be contacted. During the conversation the staff person will ask the client if she would participate in a study about Pap smears and colposcopy. If the client agrees her name and phone number will be documented for the researcher to contact later. She will be scheduled early for her return coposcopy appointment so the researcher can interview her prior to exam. Those patients consenting to be interviewed will receive \$10.00 from the researcher.

Strict confidentiality will be maintained. Only the researcher will have a list of names. All documentation will be coded. The interviews will be taped. Only the researcher and her typist will hear the tape. Conversations will be typed verbatim except for elimination of names. The tapes will be number coded for identification.

As part of the interview, a consent form and demographic form will be completed. The demographic form will be coded with the typed conversation. The consent form will be seen only by the researcher. Attached are copies of those forms.

It is anticipated that there will be approximately 10-12 subjects in the study. There will be several health care facilities contacted for accessibility of subjects. Not all clients from each facility will be contacted. This will also serve to maintain confidentiality.

**APPENDIX B**

Agency Guide for Telephone Contact  
to  
Potential Subjects for Research Study

Rules:

Client has a CIN I or cell changes warranting colposcopy follow up.

Was scheduled for initial colposcopy appointment and did not show up.

When calling do not address the failed appointment till she has been approached about the research. This could set up a negative response.

Initial Contact:

I am calling to ask if you would be willing to speak with a nurse who is working on her Master's degree and is doing a study on women who have positive Pap smears.

Answers to Possible Questions:

*What's the study about?* The study is about women's reaction to their positive Pap smears and colposcopy.

*How long will it take?* The interview will take 30 to 60 minutes. You will need to arrive at the office one hour ahead of your appointment so the interview can be done before your exam. You will be paid \$10.00 by the nurse to compensate for your time.

*Confidentiality* - All information will be confidential. She will not share with this agency anything you directly say to her. The overall results of the study will be available to us (the agency) but will not link names to findings.

Closing:

If you are willing to be interviewed then may I have your permission to notify her and schedule the appointment?

APPENDIX C

Number Code \_\_\_\_\_

1. Age \_\_\_\_\_ years.

2. Race (Please Check)

White \_\_\_\_\_ Black \_\_\_\_\_ Other \_\_\_\_\_

\_\_\_\_\_ Hispanic \_\_\_\_\_ Asian

3. Marital Status (Please Check)

\_\_\_\_\_ Single \_\_\_\_\_ Divorced  
\_\_\_\_\_ Married \_\_\_\_\_ Separated  
\_\_\_\_\_ Widow

4. Number of Children \_\_\_\_\_

Ages of Children \_\_\_\_\_

5. Highest Level of Education

(Please Check) \_\_\_\_\_ Less than 12 years  
\_\_\_\_\_ 12 years  
\_\_\_\_\_ 1-2 years Post High School  
\_\_\_\_\_ Baccalaureate Degree  
\_\_\_\_\_ Master's Degree  
\_\_\_\_\_ Greater than Master's Degree

6. Employment Status

(Please check) \_\_\_\_\_ Full-Time \_\_\_\_\_ Unemployed  
\_\_\_\_\_ Part-Time \_\_\_\_\_ Unemployed  
\_\_\_\_\_ Other

7. Total Household Income

(Please check) \_\_\_\_\_ Less than \$10,000/Yr.  
\_\_\_\_\_ \$10,000 - \$19,999/Yr.  
\_\_\_\_\_ \$20,000 - \$29,999/Yr.  
\_\_\_\_\_ \$30,000 - \$39,999/Yr.  
\_\_\_\_\_ \$40,000 - \$49,999/Yr.  
\_\_\_\_\_ Greater than \$50,000/Yr.

8. Total Number in Household \_\_\_\_\_

9. Insurance

\_\_\_\_\_ Blue Cross/Blue Shield  
\_\_\_\_\_ HMO  
\_\_\_\_\_ Medical Assistance  
\_\_\_\_\_ Medicare  
\_\_\_\_\_ Other Third Party  
\_\_\_\_\_ None

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10. Religious Preference \_\_\_\_\_

11. Distance to GYN Health Care Provider  
(Please Check)

- \_\_\_\_\_ Less than 15 miles
- \_\_\_\_\_ 15 to 30 miles
- \_\_\_\_\_ Greater than 30 miles

12. Method of Transportation to Health Care Facility  
(Please Check)

- \_\_\_\_\_ Personal Car
- \_\_\_\_\_ Cab
- \_\_\_\_\_ Bus
- \_\_\_\_\_ Neighbor or Friend
- \_\_\_\_\_ Medical Transport
- \_\_\_\_\_ Other

13. Pap Smear Results

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

(i.e., HPV or Warts,  
atypia, dysplasia, etc.)



APPENDIX D

Interview Guide

1. How did you feel when you first learned about your Pap smear results?
2. How were you told? Where were you?
3. What were you told? What do you think this means? Did you understand?
4. Did you share this with anyone? Who?
5. What did you think could happen to you?
6. What did you understand about colposcopy?
7. In your own words tell me what has influenced you and kept you from keeping your appointment.
8. Are there any other reasons that kept you from obtaining follow-up?
9. What would be the best way for you to describe your Pap smear results and what that means to you?
10. Do you have any private thoughts or feelings about your Pap smear results? Colposcopy? Your health care provider? Your body?
11. Why did you keep today's appointment rather than your last?
12. Is there anything your health care provider can do to encourage patients to keep colposcopy appointments in the future?

APPENDIX E

## CONSENT FORM

In signing this form, I am voluntarily giving my consent to be interviewed by a graduate student of Salisbury State University. I understand that I will participate in a research study that will increase the understanding of the experience of having a Pap smear.

I understand that I will be asked to describe my feelings in my own words about my Pap smear results. I further consent to the taping of this interview and I understand that the tape will only be identified by number and will not include my name. The interview will take 30 minutes to one hour to complete. I understand I might be asked to participate in a second 30-minute interview to verify the researcher's findings. I agree to complete the attached questionnaire which will also be number coded. This questionnaire will be kept separate from the interview material but will be used when the researcher proceeds with the analysis of interviews.

This interview is granted freely. I have been informed that the interview is entirely voluntary, and that after the interview begins I can refuse to answer any specific questions or decide to terminate the interview at any point. If I decide to terminate the interview, the researcher will erase my tape in my presence.

I have been assured that all my responses will remain confidential. I have been told that only the researcher, her advisor, and her typist will hear my tape and that only her research advisors will read transcripts of my tape. The tape will be erased after the researcher and her typist transcribe it. The transcripts, contents, and questionnaires will be kept in a locked file in the researcher's home. I have been told that no reports of this study will ever identify me in any way.

If I desire results of this research or have any questions about the study or about my rights as a study participant, I am aware that I may contact Mrs. Lisa Bayles, 10034 Silver Point Lane, Ocean City, Maryland 21842; telephone - (410) 213-1033.

Date: \_\_\_\_\_

\_\_\_\_\_  
Respondent's Signature

\_\_\_\_\_  
Respondent's Telephone Number

\_\_\_\_\_  
Interviewer/Researcher

**APPENDIX F**

### CONSENT FORM

In signing this form, I am voluntarily giving my consent to be interviewed by a graduate student of Salisbury State University. I understand that I will participate in a research study that will increase the understanding of the experience of having a Pap smear.

I understand that I will be asked to describe my feelings in my own words about my Pap smear results. I further consent to the taping of this interview and I understand that the tape will only be identified by number and will not include my name. The interview will take 30 minutes to one hour to complete. I understand I might be asked to participate in a second 30-minute interview to verify the researcher's findings. I agree to complete the attached questionnaire which will also be number coded. This questionnaire will be kept separate from the interview material but will be used when the researcher proceeds with the analysis of interviews. I can refuse to answer any specific questions or decide to terminate the completion of the questionnaire at any time.

This interview is granted freely. I have been informed that the interview is entirely voluntary, and that after the interview begins I can refuse to answer any specific questions or decide to terminate the interview at any point. If I decide to terminate the interview, the researcher will erase my tape in my presence. This will have no effect on my current or future care with the County Health Department.

I have been assured that all my responses will remain confidential. I have been told that only the researcher, her advisor, and her typist will hear my tape and that only her research advisors will read transcripts of my tape. The tape will be erased after the researcher and her typist transcribe it. The transcripts, contents, and questionnaires will be kept in a locked file in the researcher's home. I have been told that no reports of this study will ever identify me in any way.

If I desire results of this research or have any questions about the study or about my rights as a study participant, I am aware that I may contact the Maryland Department of Health and Mental Hygiene's Institutional Review Board at (410)225-6749 or Mrs. Lisa Bayles, 10034 Silver Point Lane, Ocean City, Maryland 21842; telephone - (410) 213-1033.

Date: \_\_\_\_\_

\_\_\_\_\_  
Respondent's Signature

\_\_\_\_\_  
Respondent's Telephone Number

\_\_\_\_\_  
Interviewer/Researcher

**APPENDIX G**

STATEMENT OF APPROVAL  
 COMMITTEE ON HUMAN VOLUNTEERS  
 SALISBURY STATE UNIVERSITY

Date December 4, 1992

MEMORANDUM TO:

FROM: Chairman, Committee on Human Volunteers

SUBJECT: Non-compliant Behavior for Colposcopy Exam in Women with

Abnormal Pap Smear Results.

Title of Study

SSU, Nursing Department

Grant Application No.

Sponsoring Agency

Dr. Edna Quinn

Principal Investigator or Program Director

Lisa H. Bayles

Student Investigator(s)

The Committee on Human Volunteers has considered the above application and, on the basis of available evidence, records its opinion as follows:

- (1) The rights and welfare of individual volunteers are adequately protected.
- (2) The methods to secure informed consent are fully appropriate and adequately safeguard the rights of the subjects (in the case of minors, consent is obtained from parents or guardians).
- (3) The investigators are responsible individuals, competent to handle any risks which may be involved, and the potential medical benefits of the investigation fully justify these studies.
- (4) The investigators assume the responsibility of notifying the Committee on Human Volunteers if any changes should develop in the methodology or the protocol of the research project involving a risk to the individual volunteers.

Francis Kane  
 Chairman



**APPENDIX H**

**INSTITUTIONAL REVIEW BOARD**  
**DEPARTMENT OF HEALTH AND MENTAL HYGIENE**  
201 WEST PRESTON STREET • BALTIMORE, MARYLAND 21201 •

January 27, 1993

Edna Quinn, Ph.D., RN, CNM  
c/o Lisa Bayles  
10034 Silver Point Lane  
Ocean City, Maryland 21842

Dear Dr. Quinn:

I have received and reviewed the revisions to your protocol entitled, "Non-Compliant Behavior for Colposcopy Exam in Women with Abnormal Pap Smear Results". These revisions meet the requirements of the Institutional Review Board and your protocol is now approved.

You are reminded of the following requirements:

1. The IRB shall suspend or terminate approval of this research if the IRB finds it is not being conducted in accordance with the IRB's requirements or that it is associated with unexpected serious harm to subject.
2. The Program Administrator shall notify the Chairperson of the IRB of contemplated substantive changes in the study that may affect the interests or rights of human subject and seek approval for the changes prior to implementing same.
3. For any projects which extend beyond one year, the Program Administrator is responsible for presenting to the Chairperson of the IRB, a completed Form DHMH 2125, Annual Review Notice, forty-five days prior to the anniversary date of the approval of this project.


Dr. Edna Quinn  
January 27, 1993  
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4. The Program Administrator shall promptly report new information of unanticipated problems involving possible risks to human subjects or others to the Chairperson.

If you have any questions, please call me at 225-6699.

Sincerely,

  
Diane L. Matuszak, M.D. M.P.H.  
Chairman  
Institutional Review Board

DLM:jab

APPENDIX I



Planned Parenthood®  
Federation of America, Inc.

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May 17, 1993

James A. Guest  
President  
Planned Parenthood of Maryland  
610 North Howard Street  
Baltimore, MD 21201

Dear Mr. Guest:

Thank you for your inquiry regarding Lisa Bayles's research study, "Noncompliant Behavior for Colposcopy Exam in Women with Abnormal Pap Results." Since this appears to be just an extension of routine follow-up (per a conversation on May 11, 1993 between Kara Anderson and Ms. Bayles) a full application as a formal research project is not required.

Sincerely,

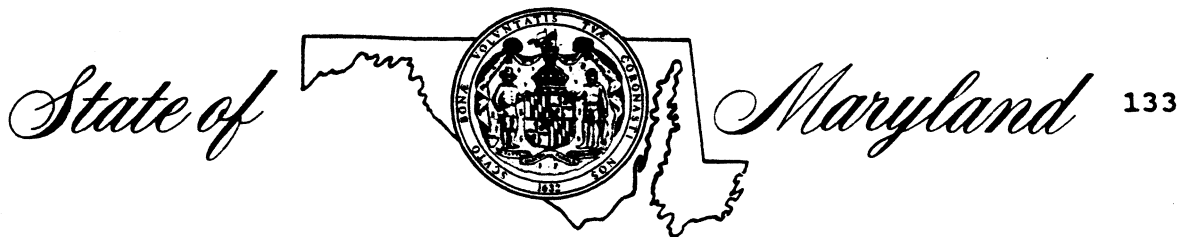
Michael S. Policar, M.D., M.P.H.  
Vice President for Medical Affairs

MSP/KLA/bad

a:\categryl\guest



**APPENDIX J**



INSTITUTIONAL REVIEW BOARD  
DEPARTMENT OF HEALTH AND MENTAL HYGIENE  
201 WEST PRESTON STREET • BALTIMORE, MARYLAND 21201 •

May 4, 1994

Lisa Bayles  
Planned Parenthood of Maryland  
Salisbury Health Center  
Court Plaza Shopping Center  
1504 S. Salisbury Boulevard  
Salisbury, MD 21801

Dear Ms. Bayles:

I have received and reviewed the modifications to your protocol entitled, "Noncompliant Behavior for Colposcopy Examination in Women with Abnormal Pap Smear Results". Your protocol is now approved.

You are reminded of the following requirements:

1. The IRB shall suspend or terminate approval of this research if the IRB finds it is not being conducted in accordance with the IRB's requirements or that it is associated with unexpected serious harm to subject.
2. The Program Administrator shall notify the Chairperson of the IRB of contemplated substantive changes in the study that may affect the interests or rights of human subject and seek approval for the changes prior to implementing same.
3. For any projects which extend beyond one year, the Program Administrator is responsible for presenting to the Chairperson of the IRB, a completed Form DHMH 2125, Annual Review Notice, forty-five days prior to the anniversary date of the approval of this project.

Ms. Lisa Bayles  
May 4, 1994  
Page 2

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4. The Program Administrator shall promptly report new information of unanticipated problems involving possible risks to human subjects or others to the Chairperson.

If you have any questions, please call me at 225-6699.

Sincerely,



Diane L. Matuszak, M.D., M.P.H.  
Chairperson  
Institutional Review Board

RJD:rjd

cc: IRB Members  
Linda Vanderhoff, Ed.D.



CURRICULUM VITAE

**LISA H. BAYLES**  
**10034 Silver Point Lane**  
**Ocean City, MD 21842**  
**[410] 213-1033**

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**EMPLOYMENT HISTORY**

**November 1991 - Present - Planned Parenthood of Maryland**  
**1506 South Salisbury Boulevard**  
**Salisbury, MD 21801**

**Position: Director/Nurse Clinician**

**Description:** Directed and coordinated the opening of the new Salisbury Center for Planned Parenthood of Maryland. Responsible for ordering the inventory, office equipment and furniture. Active in outreach and marketing activities to introduce and promote the health care services available through Planned Parenthood to the Eastern Shore Area. Management skills include: quality assurance, budget development, staffing, etc.

After one year at the Salisbury Center, opened a satellite center for the summer in Ocean City, Maryland. Acted as Director and Clinician for both sites.

As the **Nurse Clinician**, responsible for the health care provided to women of all ages. Trained to provide reproductive health care to males. Offered all contraceptive services including the Norplant and Depo Provera. Practice in an independent setting with physician consultant available by phone.

**September 1978 - Worcester County Health Department**  
**October 1991 P.O. Box 249**  
**Snow Hill, MD 21863**

**9/86 to 10/91 - OB/GYN Nurse Practitioner in the Family Planning Program.** Primary focus to provide interconceptional care for women of childbearing age. Performed counseling and physical exams for clients and performed the majority of the initial exams for adolescents. Provided in-depth counseling for clients with primary genital warts, and other STD's. Developed standard care plan for use on the Family Planning charts. Nurse consultant to clinical staff to maintain program and nursing standards. Coordinated and administered the Family Planning and Colposcopy programs. Assisted in the development of a new standardized charting system for the state Family Planning program. Committee member for the Infection Control and Quality Assurance Committees. Chair person of the Risk Management Committee.

**8/84 to 9/86 - Family Planning Program Coordinator.**  
Traveled to the four clinic sites to both manage and work in the Family Planning clinics. Performed all follow up and maintained records for the four clinic sites. Supervised three nurses, one aid and one clerk.

**4/82 to 4/84 - Clinical Charge Nurse for the Pocomoke clinic satellite center.** Supervised three nurses and two aides plus any additional staff working in the center. Provided child health care and immunization services to children in the Pocomoke area. Supervised all other services provided in the center such as prenatal care, STD's, home visits, etc.

**9/78 to 4/82 -** First employed as a contractual nurse to work in the nutritional food supplement program for Women, Infants and Children (WIC). Became coordinator for the program county wide in February 1979. Provided nutritional counseling to pregnant women and mothers with young children. Additional duties included licensing inspector for the county day care centers.

**May 1978 to** Isle of Wight Medical Center  
**November 1978** P.O. Box 470  
Berlin, MD 21811

**Position: Staff Nurse**

**Description:** Office nurse providing primary care to acutely ill patients. Duties included providing emergency care and performing lab studies and simple x-rays.

**August 1976 to** PGH MEDICAL CENTER  
**May 1978** 100 West Carroll St.  
Salisbury, MD 21801

**Position: Critical Care Nurse**

**Description:** Worked as float nurse between ICU, CCU, and SCU for the first eleven months. Remainder of employment was solely in the critical care unit.

**May 1976 to** 26th St. Medical Center  
**August 1976** 26th St. and Coastal Highway  
Ocean City, MD 21842

**Position: Staff Nurse**

**Description:** Staff nurse within a primary care center providing generalized primary acute ambulatory care and emergency services.

**EDUCATION**

- 1989-1994      **Salisbury State University**  
Salisbury, MD 21801  
**Master's of Science**
- 1977-1986      **Salisbury State University**  
Salisbury, MD 21801  
**Bachelor of Science in Nursing**
- 1985-1986      **OBY/GYN Nurse Practitioner Program**  
Planned Parenthood Federation of  
Southeastern Pennsylvania and the  
University of Pennsylvania  
Philadelphia, PA  
**Certified OB/GYN Nurse Practitioner**
- 1973-1976      **Peninsula General Hospital School of Nursing**  
Salisbury, MD 31801  
**Registered Nurse Diploma Program**

**ADDITIONAL  
TRAINING**

Attend seminars sponsored by NAACOG, State Health Department, Planned Parenthood, etc. to update skills and maintain certification.

Training through the Department of Health and Mental Hygiene for counseling and testing clients for HIV infection.

Wor-Wic Tech Community College - To obtain education in management and supervision.

**ACTIVITIES  
and  
AFFILIATIONS**

Sigma Theta Tau

AWHONN - 1986 to present

National Association for Nurse practitioners in Reproductive Health - 1987 to present

Speaker for panel discussion for State of Maryland's Norplant Caucus, workshop for Governor's Council on Adolescent Pregnancy, and Contraceptive - 1993 and 1994

Education for Salisbury Sate University's Nursing Program and local area high schools and private schools.