

Cervical Cancer Screening in Korean American Women : Findings from Focus Group Interviews

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Purpose. Korean American women have twice the rate of cervical cancer than white women and demonstrate low rates in participation in cervical cancer screening. This study was to describe the perceptions about cervical cancer and factors related to cervical cancer screening among Korean American women.

Method. Focus group methods.

Results. Five themes emerged. First, knowledge about cervical cancer; misconceptions about cervical cancer, its causes, reproductive anatomy and the treatment. Second, perceived meanings of having cervical cancer; most of the women felt that cervical cancer represented a loss of femininity and existential value of womanhood. Third, knowledge about cervical cancer screening; regular medical check-ups were necessary for early detection and prevention of cervical cancer. Fourth, experiences and perceived meanings of cervical cancer screening; the participants expressed their feelings; embarrassment, fear, shame and shyness. Fifth, practices of cervical cancer screening; various intervals in participating in cervical cancer screening. But they mentioned several deterrents, language, insurance, time constraint, embarrassment, fear of the screening results, misbelief about susceptibility, lack of health prevention behavior, and lack of information written in Korean.

Conclusion: Results emphasize the critical need for culturally appropriate health education to encourage participation of Korean American women in cervical cancer screening.

Key Words : Cervical Cancer, Screening, Focus Groups

INTRODUCTION

Cervical cancer is the second most common cancer in women worldwide, and ranks seventh in frequency among women in the United States (Herrero, 1996; Parker, Tong, Bolden & Wingo, 1997). In the US the incidence of cervical cancer was 14,500, and deaths from this disease was 4,800 in 1997 (Parker et al., 1997).

Incidence rates of cervical cancer, however, vary by race and ethnicity. According to the Surveillance, Epidemiology and End Results (SEER) program, 1988-1992 comparisons, the incidence rate per 100,000 (age adjusted to 1970 US Population) in Hispanic women was, 16.2; Alaskan Native, 15.8; African American, 13.2; and Caucasian, 7.5. Among Asian ethnic groups, the incidence rate was 43.0 among Vietnamese women, followed by Korean American women, 15.2. The inci-

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dence rates were less than 10 per 100,000 for women of Chinese, Filipino and Japanese descent (Rosenthal, 1998).

The incidence rates of cervical cancer varies also by age. Among women, 30 - 54 years, the incidence is 3.8, and between 55 - 69 years, 6.2 per 100,000. Vietnamese women have the highest incidence of cervical cancer between 30 - 54 years of age (56.4 per 100,000), while Korean women rank second, 15.6 per 100,000. Between 55 - 69 years, the incidence rate of cervical cancer is 181.6 among Vietnamese women, and 55.2 in Korean women (Miller et al., 1996; Rosenthal, 1998). The high incidence of cervical cancer among Korean women is replicated in US community studies, and in a cancer registry study conducted in Seoul, Korea (Kim et al., 1996; Perkins, Morris, Wright & Young, 1995). Despite the high incidence of cervical cancer in Korean American women, little is known about their perceptions of cervical cancer and related health preventive actions. The purpose of this study is to describe the perceptions about cervical cancer and factors related to cervical cancer screening among Korean American women.

The research problems are followed :

- 1) How the Korean American Women perceived about the cervical cancer and the cervical cancer screening ?
- 2) What are the factors related to cervical cancer screening among Korean American women ?

LITERATURE REVIEW

Carcinoma of the cervix is causally related to infection of the cervix by the human papilloma virus (HPV) (National Institutes of Health Consensus Development Conference Panel, 1996). Associated risk factors of cervical cancer are early age of sexual activity, multiple sexual partners, and cigarette smoking (Schiffman & Brinton, 1995). Reducing the rate of HPV infection by changes in sexual behaviors would decrease the incidence of this disease. Papanicolaou (Pap) smear testing, moreover, is the best available method to detect preneoplastic cervical cancer.

Reversing the incidence of cervical cancer is one goal of Healthy People 2000, the health promotion and disease prevention initiative of the US Public Health Service (US Department of Human and Health Service, 1991). A specific objective of the initiative is to increase to 95% or more the proportion of women who ever receive a Pap test, and to increase to 85% or more those

who received a Pap test within the preceding 1 to 3 years. The U. S. Preventive Services Task Force recommends Pap tests for all women when they become sexually active and no later than 18 years of age and then every 3 years for women at normal risk for cervical cancer. The interval between tests may be shorter for women who at high risk for the disease (US Preventive Task Force, 1996).

Not all women in the US receive Pap test screening. The National Health Interview Survey (NHIS) showed that from 1987 to 1992 nearly 90% of women reported ever having a Pap test, but the proportion having a recent screen in the last year was considerably lower, 38% in 1987, and 43% in 1992 (Martin, Wingo, Calle, & Heath, 1996). The unscreened subpopulation consists primarily of older women, widows and never-married women. Women with less than 12 years of education, impoverished, uninsured and without a usual source of medical care also underutilize the Pap test. Other unscreened women are those who live in rural areas and those from communities of color (Brown, 1996).

Recent analysis of trends in self-reported use of the Pap test showed that Asian Pacific Islander (API) women, 18 years and older, lag in receiving this test. In 1997, 81.6% of the API women versus 93.7% of white women reported ever having a Pap test. In comparison to 83.9% of white women, only 69.2% of API women reported having a Pap test within the past two years (Blackman, Bennett, & Miller, 1999).

National and local community rates of participation of Korean women in Pap test screening are lower than Healthy People 2000 objectives. In a California study on Koreans, 40% of the women reported never having had a Pap test, compared with 8% of California women (Kang et al., 1997). Findings from a population-based telephone survey of Korean women in two California counties, showed that only 50% of 818 women in the final data analysis reported a Pap test in the past two years (Wisner et al., 1998). Smyser, Krieger and Solet (1998) found that 67% of the Korean women reported ever having a Pap test, and 58% also reported having this test within the previous three years.

Four categories identify the common barriers to Pap smear screening among Asian-Pacific Islander women: lack of knowledge of cervical cancer by the women or health provider; economic barriers; logistical barriers; and the belief system of a cultural group (Brown, 1996). Women with low utilization of the Pap test are more

likely to be unaware of the medical procedure, do not understand that it both detects precancerous conditions and is a cancer detection method. Women also report that they do not receive the Pap test because their physicians never told them to get it (Harlan, 1991). The cost of the procedure may also deter women from getting the test. It may have a lower priority than securing food and paying rent among impoverished women, and securing screening may be inaccessible to those who live in rural areas. Other conditions related to low utilization of Pap smear screening are logistical factors, such as lack of transportation, lack of child-care, and inability to leave work or neglect household obligations. Powerful cultural barriers to getting a Pap test are fatalistic and fearful attitudes about cancer. Modesty and fear of discomfort during the Pap test also are personal barriers. Among immigrant women, inability to speak English, preference for speaking native languages during the clinic visit, recent immigration to the US, and cloistered living in ethnic communities are related to low utilization of the Pap test (The National Cancer Institute Cancer Screening Consortium for Under-served Women, 1996).

Among Asian and Pacific Islander communities in the US, the Korean American community is the fifth largest and comprises 11% of the API population. (US Bureau of the Census 1991. In 1990 almost one-third of Koreans lived in California, 79% were foreign born, and 89% of those age 5 and older spoke a language other than English in the home and did not speak English well. These characteristics are shared by the Koreans who live through out the US. (US Department of Commerce, 1993).

In recent years few studies have been conducted on Pap testing among Korean American women. Findings from a population-based telephone survey of Korean American women in two California counties showed that the strongest correlates of getting a Pap test was having had a regular check up in the previous two years and being married, employed or both (Wisner et al., 1998). Further investigation of other factors that might contribute to low Pap test participation among Korean American women is warranted given the high cervical cancer rate among them, and the proportionately large population of Koreans in the US.

METHODS

This qualitative study used focus group methods to describe the experiences of Korean American women with cervical cancer and Pap smear screening. The aim of a focus group is to generate detailed and in-depth descriptive data about a wide range of perceptions and attitudes related to a topic. A moderator guides group participants who are similar to each other to respond to questions. Their responses prompt discussion and interaction among them. Participants reflect on personal experiences, give impressions, and describe feelings, opinions and ideas. The group process leads to deeper exploration of issues and range of experiences. Findings from a focus group are descriptive conceptual themes and cannot be generalized to a population. The results, however, are fruitful to develop formal interview and survey questionnaires, supplement quantitative findings, research hypothesis for additional studies, and vocabulary or methods for health education programs. (Krueger, 1994; Scrimshaw & Hurtado, 1987).

The study was conducted during April 1998 in Seattle, by four nursing scholars from Korea who visited the University of Washington School of Nursing. Four researchers worked together to prepare for conducting the research for 6 months, such as group studies with related references and videotapes, open discussions with specialists in focus groups, role plays for moderating skill, and participated several seminars for focus group research method.

The investigators worked with a church and parent association of a Korean language school to recruit participants for the project. The investigators met with the pastor of the church and the chair of the women group to explain the goal and procedure of the study, gain their cooperation and receive guidance in conducting the study. At a monthly meeting, the chair of the women church group invited women from the congregation to participate in the project. The investigators met with the principal of the Korean language school who recommended a meeting with the leader of the parent association to assist with participant recruitment. The leader of the association recruited the women who were mothers of children attending Korean language school.

The researchers got the permission from the Human Subject Review Committee, the University of Washington. Participant criteria included the following ;

women 18 years or older, fluent in the Korean language for the free group discussion, born in Korea, and residence in the US for more than 5 years for the sufficient experience of living in the US.

A total of 16 women participated in the study, 8 each from the church and the parent association. The average age of the women was 46.1 years and ranged from 35 to 76 years. Their education ranged from primary school to college education: 3 completed primary school; 11 completed high school; and 2 were college graduates. Their residence in the US ranged from 6 to 29 years, with an average residence of 16.8 years. Fourteen of the women were married, 1 was widowed, and 1 woman was separated.

Each focus group of women participated in two sessions during a two-week period. Each session lasted 1.5 hours. One week before the first session, each participant received a letter and telephone call to clarify the goal and procedure of the study, and to confirm attendance. The church group met at the church, and the school group met in the school conference room. Participants and moderators sat around a long table so that all could see and hear each other. Two investigators moderated the focus group, and two other investigators recorded observations of group interaction.

At the beginning of the first session of each focus group, the investigators greeted participants and offered refreshments. After the group settled, the investigators explained the purpose of the focus group, and the roles of participants, moderators and assistants. Group process rules, informed consent, and confidentiality were explained. Participants gave written consent for participation in the project and audio-taping of the sessions. Each participant received a small gift worth 10\$ for participation.

The sessions were conducted in Korean. The first session was used to probe the thoughts and feelings of the women about cervical cancer and the Pap test. The following broad questions were asked of the women: "Have you ever heard of cervical cancer?" "Have you ever heard about cancer screening test?" "Why do you think that Korean American women do not get cervical cancer screening?" The investigators developed another set of questions for the second session after a debriefing discussion about the first meeting. The questions for the second session focused on the women experience with their first Pap test, and the motivation for receiving it for the first time.

Four investigators listened to the audiotapes separately and together in a group. Each tape was transcribed verbatim in Korean. They listened to the tapes, read the transcriptions together, and coded meaningful statements. Coded data were grouped into clusters of themes with common meanings. Investigators who were moderators of the focus group had primary responsibility for the data analysis process. Disagreements in coding were resolved through discussion between moderators. For this article, salient themes and response exemplars were translated into English.

The women were willing to talk about their thoughts, feelings and experiences. The women knew each other from either church or the parent association but they never had opportunity to talk about cervical cancer and cervical cancer screening. The women were initially reticent, but they adapted quickly and by the second session they were eager to talk. To begin discussion, the moderators asked, "What do you think about the word cervical cancer, what comes to your mind?" That question led to a flood of thoughts and feelings from the women.

RESULTS

The focus groups yielded 5 themes about cervical cancer and cervical cancer screening: (1) knowledge about cervical cancer; (2) perceived meanings of having cervical cancer; (3) knowledge about cervical cancer screening; (4) experiences and perceived meaning of cervical cancer screening; and (5) practices of cervical cancer screening.

Knowledge about cervical cancer

The women had misconceptions about cervical cancer, its causes, reproductive anatomy and the treatment of cervical cancer. Most of the women had never heard about the cause of cervical cancer and had never heard about cervical cancer until discussions in the focus groups. One woman mentioned that she had some knowledge about cancer, but was not familiar with cervical cancer. This woman said, "I've only heard about cervical cancer, [I know] much less what symptoms there are or how it occurs --- never did I have the chance to think about cervical cancer."

Most of the women mentioned that heredity, predisposition and resistance to disease are related to cervical cancer. The women stated: "If you are a healthy person, the power of resistance allows one to fight back." "It

depends on the predisposition towards illnesses. The incidence rate of cervical cancer is related to family history. "In addition, the women stated that cervical cancer was caused by physical problems, such as uterine infection, induced abortion, dysmenorrhea and poor hygiene.

Some of the women mentioned that people who were promiscuous or had unusually frequent and prolonged intercourse would have higher occurrence of cervical cancer. Other women stated that people with "no sexual experience" or had "prolonged abstinence even though they had had prior sexual experience" would have high occurrence of cervical cancer. One participant mentioned that absence of sexual activity may cause cervical cancer. Some of the women, however, conceded that cervical cancer is probably not caused by sexual behavior, and expressed interest in the real causes of cervical cancer. Most of the women thought that the treatment of cancer is difficult. The woman had a high risk of death. They understood, however, that cervical cancer is treatable if detected early, and if the cancer is taken out of the uterus.

Perceived meanings of having cervical cancer

The women were horrified when they heard the phrase cervical cancer. Most of them felt that cervical cancer was "a horrible disease" and "a death penalty". Most of the women felt that cervical cancer represented a loss of femininity and loss of existential value of womanhood. One woman said, "I heard many times, if there is something wrong with the uterus, it means the end of womanhood, the difference between women and men is the uterus. There was a woman who just turned 30 when she had to remove her uterus; she and her husband became upset, as if their world ceased to exist. People around her told her that her womanhood was over. She contemplated divorce within such a painful situation." Other women had only a vague idea about cervical cancer. They had never thought of themselves to be potential cervical cancer patients. They thought that "I will be O.K. because there was no cervical cancer patient in [the] family."

Knowledge about cervical cancer screening

Women who had regular medical check-ups (Pap Test) had general knowledge about cervical cancer screening. They thought that regular medical check-ups were necessary for early detection and prevention of cervical can-

cer. Negative cancer screening results gave them comfort and peace of mind for an entire year.

The women knew that screening involved the Pap test. Only those women who had had cervical biopsies knew that these were required to follow-up on abnormal Pap tests. These women stated that the pap smear test is not painful because it only extracts a few cells, but the biopsy test is a painful procedure. One of the participants knew that women should get cancer cervical screening because some cells still exist even with the uterus and fallopian tubes removed.

Even among those participants who received regular medical check-ups, some did not know the anatomical structure of the uterus, nor were they aware of which areas involved cervical cancer screening, and what methods were used. The women said, "Even if I want to know the exact procedure involved in testing, I just let the doctor do what ever he is doing. Because I don't know about cervical cancer nor test procedures. I have no choice but to sit still and follow the doctors directions." One of the women asked if washing the genital area before the test would affect diagnosis.

The women did not know the screening schedule nor who should have cervical cancer screening. They thought that a virgin is excused from screening, but they were unsure whether an older virgin should be screened. One participant said, "In my knowledge I think a virgin shouldn't do it. My little sister was 28 and still single. Even though the doctor recommended it, she worried about what to do, if her hymen ruptured [with the procedure]." The participants thought that the appropriate time to begin screening was after the birth of a baby or in the late thirties or older. Participants had mixed understanding of screening after menopause: some women thought it should continue, others thought that it could stop. One woman said, "I don't have to do it more often if there is no problem after one or two yearly test." Another woman asked, "Is it too often to do it once a year?"

Experiences and perceived meanings of cervical cancer screening.

All of the participants expressed their feelings about the Pap test procedure. They felt embarrassment, fear, shame and shyness. One participant said, "I do get regular check-ups but I hate to take off my underwear and lie on the table. He [The doctor] is not my man. I feel so shameful."

Another participant said, " *In my case, once I make an appointment at the gynecologist and set the date, I get sick when nothing was wrong with me before. By that morning before my appointment I can actually measure a temperature. I have a fever. I feel sick for no good reason until I get checked-up, pay and leave. Then I 'm perfectly fine again.* " A woman felt relieved after the Pap test. She said, " *I have peace of mind for one entire year.* "

Practices of cervical cancer screening

The women reported various intervals in participating in cervical cancer screening. Among the women who received the Pap test, few reported getting screening at various intervals: 6 months, one year, two years or once in a while when prompted by news that friends or relatives had cervical cancer.

The women mentioned several deterrents to cervical cancer screening.

Language. Most of the Korean women reported that they could not communicate with American doctors. One participant said, " *Language is a problem. My sister never wants to go alone. She has problems communicating with the doctor. This makes her embarrassed and frustrated that she considers it just one big hassle, so she would rather not deal with it.* " The women also preferred Korean doctors who spoke the language.

Insurance. Not having insurance impaired participation in cervical cancer screening. One woman said, " *Of course, [one without insurance] cant go. Its hard for someone in a family without insurance to do it voluntarily. She has to go when shes ill. Yes, she only goes when shes ill and in an emergency, without such she just lets things go -- shell let things pass even when she knows [she should].* " Women also mentioned that insurance did not guarantee testing because the insurance policy does not allow them to freely choose the hospital or doctor.

Time constraint. Most of the participants reported busy lives. They have many roles to fulfill in the home and work. Many of the women managed small businesses with their husbands. They said, " *We are too busy. We forget the test also, it is hard to spare the time during business hours.* "

Embarrassment and Privacy. Women felt embarrassed about the awkward position, and manipulation and exposure of genitals to male physicians during the Pap test.

Fear of the screening results. Women mentioned that

they are fearful of an abnormal finding which prevented them from being screened. One participant said, " *I am afraid and [I] make up all kinds of excuses for not having a screening, such as time constraints. If something comes up, I cancel the appointment right away.* "

Misbeliefs about susceptibility. Some of the women believed that they were not susceptible to getting cervical cancer and did not think of themselves as ever getting cervical cancer. The women believed that they were not susceptible because there was no familial history, and they ate right, exercised and kept themselves clean.

Lack of health prevention behavior. Most of the women only go the hospital, doctor or clinic when they are sick. If they are not sick, they do not seek medical care.

Lack of information written in Korean. The women participants preferred to speak and read Korean. Health information in English distributed through television, radio, newspaper or health brochures are not accessible to the women.

CONCLUSION

Korean American women have twice the rate of cervical cancer than Caucasian women in the US, and a lower rate of participation in cervical cancer screening. A population-based study of Korean American women showed that the strongest correlates of getting a Pap test was having had a regular check up in previous two years and being married, employed or both (Wisner et al., 1998). Findings from this study using focus group interviewing revealed conditions that illuminate further reason behind the low rates of cervical cancer screening in Korean American women.

Barriers to cervical cancer screening in Korean women are similar to those found among women in general. The Korean women had poor knowledge and misconceptions about reproductive anatomy, causes of cervical cancer, their susceptibility, cervical cancer treatment, screening schedule, and the recommended age for screening.

The women cited economic and logistical impediments to screening, including concerns about cost, the lack of insurance, and time constraints. They women reported many hours fulfilling family obligations and working in small family businesses which are a frequent method of economic support in this community.

The women described influential cultural beliefs and cultural barriers. Discussions about reproductive func-

tions are rare among Korean women. Sexual organs are a private matter and are not a topic of discussion even among women. Many of the women had fatalistic and fearful attitudes about cancer. They reported shame and embarrassment about the screening procedure. The women were uncomfortable with both American and Korean physicians. Although they preferred Korean physicians, the women said that these physicians gave little information, and did not make clinic appointments which caused long waiting times. Some of the women perceived American physicians as knowledgeable, gentle and kind, but their inability to communicate in Korean was a source of frustration. The unavailability of health information written in Korean left the women ignorant of health information. The lack of health prevention orientation among the women was also a deterrent to screening participation. The women reported that it is customary to only go to the clinic, doctor or hospital when they are sick. Kim, et al. (1999) found that the most frequently cited reason for not having the Pap smear test in Korean American women was the absence of disease symptoms. The lack of prevention orientation has also been mentioned as a critical issue in low Pap screening rates among Vietnamese women (Yi, 1994). Yi suggests that Vietnamese physicians do not receive education about health promotion in Viet Nam, and do not encourage it in their patients. Findings from this study affirm the consistent pattern of barriers that prevent women from getting cervical cancer screening. The results emphasize the contribution of cultural barriers to disease prevention activities in yet another group of immigrant women.

The limitations of this study are inherent in the focus group method. The small convenience sample and the qualitative data preclude generalization to the population of Korean American women. The intent of this study, however, was to explore the conditions that might contribute to the cervical screening practices of Korean women. The results of this study highlight the knowledge, attitudes and practices about cervical cancer and cervical cancer screening among Korean American women. This information may provide the conceptual basis for population surveys and health education programs. The experiences and thoughts communicated by the Korean American women clearly emphasized the salient issues for a health program aimed at cervical cancer prevention: health insurance and culturally appropriate information tailored to the beliefs and attitudes of

the Korean culture. Chen et al. (1997) describe a collaborative project that employed participatory action research principles to improve breast and cervical screening in a Korean American community. The project emphasizes Korean community participation in the development of culturally sensitive health education programs. Community-based health education may be disseminated through organized social networks involving churches, associations and small businesses. A cultural phenomena in the Korean American community are video dramas of Korean family life. Popularity of this entertainment form suggests that videos may be a useful medium for cancer education. Education may also engage Korean health providers to Pap testing among women patients. Creating culturally appropriate and language sensitive programs, and involving the community is imperative to reach women and their families to reduce cervical cancer mortality in the Korean American community.

This paper reports findings from a study using focus groups with Korean American women to describe their perceptions of cervical cancer and their participation in cervical cancer screening. Findings from this study may serve as the basis for a population-based survey questionnaire, and culturally appropriate health education programs to reduce cervical cancer mortality in Korean American women.

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