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"It Is Good if Everyone Knows"

An Exploration of Cervical Cancer Screening Among Women in an Urban Sikh Community

by

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ABSTRACT

Cervical cancer is preventable when women are regularly screened. As immigrant populations in Canada are growing this is an important area for study. A qualitative descriptive study was conducted with women in a large urban Sikh community exploring perspectives on cervical cancer screening and strategies to reach women. In-depth interviews were conducted with 13 women and 3 focus groups were completed. A prevailing theme of inside/outside was found where knowledge, lack of prevention, influence of the family and community, and provider issues all impacted a woman's ability to move outside to obtain cervical cancer screening. Immigrant women are at high risk for cervical cancer due largely to insufficient screening and lack of opportunities available for screening. Strategies to reach women recommend a variety of methods including nurse provided services. Information collected will be helpful in planning and delivering screening services to women in the Sikh community.

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DEDICATION

This thesis is dedicated to Garry, Kirsten and Megan, my family who supported me greatly through this process with understanding and patience. I would also like to thank my committee for their valuable advice and contribution to this publication. Last, but not least I would like to dedicate this work to the many women in the Sikh community who contributed to the research process in numerous ways. You have been my inspiration and taught me much about your culture.

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CHAPTER ONE—INTRODUCTION

Cervical cancer[1] is an important woman's health issue, one that is largely preventable when women are regularly screened. Immigrant women may be at high risk for cervical cancer due largely to insufficient screening and lack of opportunities available for screening. The immigrant population in Canada has increased over the last number of years and the trend is predicted to continue. The South Asian[2] group including the Sikh[3] community is no exception. The literature provides limited information about screening behaviours, particularly cervical cancer screening, in Sikh women. This type of information would be helpful to develop programming and outreach strategies for Sikh women in large urban centres.

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[1] Cervical Cancer—There are two types of cervical cancer. Carcinoma insitu, is a cancer that has only affected the surface cells of the cervix. In invasive cervical cancer, abnormal cells have spread beyond the surface of the cervix, deeper in the cervical tissue and to other surrounding tissues or organs (Alberta Cancer Board, 2000).

[2] South Asian—The Canadian South Asian population is a diverse group of individuals with various religious beliefs, languages and cultures. All have originated from the Indian subcontinent (Talbani & Hasanali, 2000).

[3] Sikh—Sikhism began as a separate religion in India approximately 500 years ago. Most Sikhs live in Punjab and speak Punjabi. Many who have immigrated to Canada were previous landowners who lived in rural communities. For Sikh individuals there is little difference between religious and cultural beliefs (Coward & Sidhu, 2000; Multicultural Awareness Program--Peter Lougheed Hospital, 2000)

Background

With an increase in immigration and globalization, Canada's population is changing. Statistics Canada (2002) reports a 14.5% increase in the number of immigrants in Canada from 1991 to 1996. Multilingualism increased by 15.1% in the same time period. In the 1996 census, 11.2% of Canada's population and 10.09% of Alberta's population were visible minority. The South Asian community accounted for approximately 2.3% of Canada's total population and 1.97% (52,565) of Alberta's total population (2,669,195). There are numerous groups that comprise the South Asian population, one of the largest being the Sikh community. Punjabi is the mother tongue of the Sikh community and 0.8% of Canada's population speaks Punjabi. In 1996, Chinese was the fastest growing language in Canada followed by Punjabi, Arabic and Tagalog Statistics Canada, 1996). Although the migration of Sikhs from India began 100 years ago, the majority immigrated to Canada in the 1970s (Council of Sikh Organizations, 1997/1998). Today, members of this community continue to emigrate from India to Canada, to large urban centers in particular.

The health of immigrant groups, including the Sikh community, is an important focus for health care professionals. Barriers to access and other factors are common among first generation Canadians (The Calgary Multicultural Health Care Initiative, 1999). Barriers influence immigrants' health seeking behaviours and the care they receive. This is also the case for screening practices; studies have shown that immigrant women are less likely to participate in cervical cancer screening (Goel, 1994; Harlan,

Berstein, & Kessler, 1991; Kim et al., 1999; Mandelblatt et al., 1999; Maxwell, Bancej, Snider & Vik, 2001; McAvoy & Raza, 1991; Pham & McPhee, 1992; Schulmeister & Lifsey, 1999; White, Fishman, Guthrie, & Fagan, 1993; Yi. 1994).

In the year 2002, it is estimated that 1400 new cases of invasive cervical cancer will be diagnosed in Canada and 410 deaths will occur from the disease (National Cancer Institute, 2002). This is a slight decrease from 2001 estimates for both incidence and mortality. In Alberta in 1998, 131 women were diagnosed with invasive cancer and 42 women died from the disease. In addition, approximately 1500 cases of carcinoma in-situ (superficial cancers of the cervix) were diagnosed (Alberta Cancer Board, 2002). Most cases of cervical cancer are preventable with regular screening (Health Canada, 1998).

The National Population Health Survey (NPHS) conducted in Canada in 1996-97 sampled 33,817 women aged 18 and older about participation in cervical cancer screening (Maxwell, et al., 2001). Researchers found that about 13% of women surveyed had never had a Pap test[4] and that 28% had not been screened in the last 3 years. These rates are only marginally decreased (1-2%) since the last national survey in 1994 (Snider, Beauvais, Levy, Villeneuve & Pennock, 1996). Groups at higher risk for non-

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[4] Pap test—This test is sometimes called a Pap smear and takes a small sample of cells from the cervix (small narrow portion at the bottom of the uterus or womb) using a spatula and brush. The cells are examined under a microscope for any changes. The Pap test can detect cell changes (dysplasia) before they become cancer (Alberta Cancer Board, 2000).

participation included single and older women, those who were born outside Canada, did not speak English, had lower education and those who did not participate in prevention activities. Screening rates for specific ethnocultural communities were not collected.

In 2000 a knowledge, attitudes and behaviours survey (WKAB) was conducted with Alberta women age 40-69 (Alberta Cancer Board, 2001). Eighty-nine percent of women in all age groups reported having a Pap test within the last three years. Common reasons for not having the test were lack of time or procrastination and not knowing they needed one. Rates of screening were inversely linked to age, with a 12% decrease in screening rates with increasing age (Pim, 2001).

Pap screening was also measured by the 1990 Ontario Health Survey where participation in screening was measured in women 16 years of age and over (n = 24,430). Socio-demographic data were analyzed to determine predictive factors for screening by women who had indicated they ever had a Pap test (Goel, 1994). Researchers found that immigrant women (defined as those who have lived in Canada 10 years or less) and those who did not speak English or French were less likely to have ever had a Pap test.

Research Purpose and Questions

The purpose of this study is to explore the knowledge, understanding and perceptions of Sikh women on cervical cancer screening. Data were also collected on Sikh women's preferences for culturally based cervical screening services. The following research questions guided data collection and analysis:

1. What are Sikh women's perspectives on cervical cancer screening and the Pap test?
2. If Sikh women would like cervical cancer screening resources and services delivered in their community, what preferences would they express regarding the provision of this service?

Answers to the above questions will provide an essential foundation for planning an effective screening service for women of the Sikh community.

CHAPTER TWO—LITERATURE REVIEW

Cervical cancer is an important health issue for women, especially certain groups of women. As observed in cancer prevention practice, women of ethno-cultural communities tend to participate in screening less often than Caucasian women. Ethnocultural women often say they seek health services only when a problem exists and when symptoms are present. In this literature review I will address topics pertinent to cervical cancer screening in the Sikh community.

Scope of the Problem

Invasive cervical cancer incidence rates were compared between South Asian women and the general population in British Columbia (Hislop, Deschamps, Band, Smith, & Clarke, 1992). Age standardized incidence rates for South Asian women were 1.8 times higher than those of the general population; in certain age groups the rates were as much as 4.5 times higher. The authors suggest the higher rates are likely due to inadequate screening and follow-up of abnormal Pap tests. This data provided the necessary background for the establishment of the South Asian Pap Test Clinic (Bottorff, Balneaves, Sent, Grewal, & Browne, 2001) which offers cervical cancer screening by a female physician or nurse.

Cancer Screening in South Asian Women

Choudhry, Srivastava, and Fitch (1998) conducted a descriptive, exploratory study in Ontario of 57 South Asian women age 40 and over to assess their knowledge, attitudes and beliefs on breast cancer. A questionnaire was designed, pre-tested and

administered to the women recruited via a network sampling technique. Proficiency in English ($p = 0.009$) and the length of residence in Canada ($p = 0.009$) were significantly related to breast health practice scores. Women stated cancer was a serious disease but if a woman was not experiencing symptoms she would likely not engage in screening behaviours. A limitation of this study is its small sample size.

A qualitative, ethnoscience study was completed in Vancouver with South Asian women on their perspectives of breast health practices (Bottorff et al., 1998). Fifty South Asian women were interviewed and focus groups were conducted with an additional 30 women. Fifty percent of the women were from the Sikh community. The findings included; women's purpose in life, being modest and placing others (family) first; cancer is not discussed outside the family; it is important to maintain a strong family lineage; by attending screening services it means they actually have the disease; if one focused on cancer or talked about it she may actually get the disease; a diagnosis of cancer was considered to be part of one's own destiny; and in the absence of symptoms, women considered themselves healthy. "The notion of screening was foreign to these women" (Bottorff et al., 1998, p.2081).

These two studies (Bottorff et al., 1998; Choudhry et al., 1998) provide an in-depth look at South Asian women's perspectives on breast health. Language and length of stay in the host country were identified as key variables related to breast cancer screening. Other challenges include priority on prevention, role of women in the family and modesty. The extent to which information about breast cancer screening practice is

relevant to cervical screening is unknown. Information collected on Sikh women and cervical cancer screening in the current study will be compared to the information on breast health to increase understanding of the challenges for women to screening in this community.

Cervical Cancer Screening in Ethnocultural Women

It is apparent from the literature review thus far that only a small number of studies exist about South Asian women and cancer screening. Even more limited information was found related to Sikh women and cervical cancer screening. Therefore, a review of cervical screening literature in other ethno-cultural groups was carried out to identify insights that may help to inform research with Sikh women.

Smith, Phillips and Price (2001) analyzed published articles, books and reports to determine sociocultural factors affecting breast and cervical cancer screening among women of minority ethnocultural and racial groups; nine different groups in the United States were included in this review. Lack of knowledge, embarrassment, traditional folk medicine and decision-making processes (family or authority within the group) were common barriers to women of all cultures studied. They found the family, including family support and how decisions are made, was a significant influence on screening in many cultures. Those families who believed that health and disease are determined by chance had a less established relationship with a health care professional because they did not believe that they or their physician could alter health outcomes.

African American Women

Among black American women cervical screening rates were varied. Studies (Harlan et al., 1991; Mandelblatt et al., 1999; White et al., 1993) conducted in the United States found that black American women were less likely to participate in cervical screening than Caucasian women. On the other hand, Paskett, Rushing, D'Agostino and Tatum (1997) found no significant difference between the screening rates of African American women and Caucasian women. In fact, fewer Caucasian women in this study were screened as opposed to their African American counterparts. Race was not a significant predictor of screening behaviour in this study. Participants interviewed in this study (n=320) all lived in low income housing and represented a range of ages. These results indicated other variables such as low-income and age also contribute to participation in screening. When conducting research with women of various ethnocultural groups it is important to keep in mind that low income and ethnicity may overlap.

Hispanic Women

Studies of Hispanic women in the United States (Harlan et al., 1991; Mandelblatt et al., 1999; White et al., 1993) also report low participation rates in cervical cancer screening. Mandelblatt et al. (1999) reported length of stay in the United States as an important variable in predicting screening practices. Those women who have lived in the United States for a longer period of time are more likely to participate in screening than those who had recently immigrated. Harlan et al. (1991) found language to be an

important factor in predicting screening behaviours in this population. Women who spoke Spanish were five times more likely not to have been screened as compared to women who spoke English.

Asian Women

Tang, Soloman, Yeh and Worden (1999) examined cultural variables related to breast and cervical screening in young Asian women in the United States. Openness of sexuality, value of prevention and level of acculturation were directly correlated with participation in screening. In comparison, Caucasian women stated modesty was less of a concern, they had more communication with their mothers on these topics, they valued prevention and more commonly used Western medicines.

Vietnamese women are also less likely to be screened than women in the general population. Studies (Pham & McPhee, 1992; Schulmeister & Lifesey, 1999; Yi, 1994) found that 50-54% of the women surveyed and interviewed had never had a Pap test. Pham and McPhee (1992) found that women who had lived in the United States for a shorter period of time (<10 years) were less likely to be screened as compared to those who immigrated 10 or more years ago. Schulmeister and Lifsey (1999) determined in their sample (n=96) that 91% of women aged 65 and over (n=11) had never had a Pap test. All three studies utilized small samples and therefore generalizability of the results is cautioned.

Two studies were also conducted with Korean women in the United States to investigate cervical cancer screening rates and barriers to participation.

Kim et al. (1999) interviewed women (n = 159) in their homes. Forty-five percent of these women had never had a Pap test and only 26% had had a Pap test in the last three years. English proficiency was significantly correlated with ever having a Pap test.

In reviewing the literature on ethnocultural communities and cervical cancer screening several variables were identified impacting women's screening participation. These include ability to speak English, length of stay in the host country, openness to sexuality and lack of health promotion philosophy. Income and age were also shown to influence women having a Pap test. These variables will be important to explore further in assessing Sikh women's perspectives on cervical cancer screening in this current study.

Summary

Studies on cervical cancer screening conducted in the various ethno-cultural communities in the United States have identified a variety of variables that impact screening. These include lack of knowledge, embarrassment and modesty, family influence, value on prevention, length of stay in the host country, acculturation, language, age and income. These key areas should be addressed in questions to participants in the current study to begin to understand more fully the barriers for Sikh women seeking cervical cancer screening. In the preceding literature review, it is clearly apparent that a gap in research of Sikh women in large urban centres in Canada and cervical screening exists. Cancer screening in general by a wide variety of ethnic women suggests there are many challenges for women to access and attend screening. Due to the lack of data in

the Sikh community an exploratory descriptive study is warranted.

CHAPTER THREE—THEORETICAL FRAMEWORK

Several perspectives provide the foundation for this study: Leininger's (Leininger & McFarland, 2002) theory of transcultural nursing, critical social theory (Freire, 1994), empowerment education (Wallerstein & Berstein, 1994) and health promotion theory (World Health Organization, 1986). Each contributes in some way to the approach, the focus and desired outcomes of the research.

Leininger's (1991) theory of transcultural nursing and the Sunrise Model (Appendix A) provide a framework to develop cultural knowledge to guide nursing practice. The concept of care is central to nursing and if based on cultural foundations will facilitate the health and well being of individuals and groups of diverse cultures (Cameron & Luna, 1996). Leininger (1991) defines nursing as:

> A learned humanistic and scientific profession and discipline which is focused on human care phenomena and activities in order to assist, support, facilitate, or enable individuals or groups to maintain or regain their well being (or health) in culturally meaningful and beneficial ways. (p. 49)

Leininger describes clients as human cultural beings encompassing individuals, families, groups, communities, and beyond. Humans are cultural beings with varying "cultural values, beliefs and lifestyles" (Cameron & Luna, 1996, p. 186).

The environment is another key component of the transcultural nursing model. Human behaviour is only understood in the context of culture and the environment (Cameron & Luna, 1996). Environmental context is defined as (Leininger, 1991):

> ...the totality of an event, situation, or particular experiences that gives meaning to human expressions, interpretations, and social interactions in particular physical, ecological, socio-political and/or cultural settings. (p. 48)

Health is defined as (Leininger, 1991):

> ...a state of well being that is culturally defined, valued, and practiced, and which reflects the ability of individuals (or groups) to perform their daily role activities in culturally expressed, beneficial, and patterned lifeways. (p. 48)

Other key concepts include culture, social structure, and worldview. Central to the theory is "care"—human care based on the lived experience of the individual or group that cannot be understood without extensive time spent with a cultural group to gain a multifaceted knowledge of the community (Cameron & Luna, 1996).

Based on the transcultural nursing model, diverse influencers on Sikh women's cervical cancer screening behaviours need to be explored by the researcher. This process will help to ensure a holistic approach to the health of women in the Sikh community. Cultural values, beliefs, structure of the family and community, environment, and language need to be included in the inquiry to gain a deeper understanding of the challenges for Sikh women seeking cervical cancer screening.

Critical social theory (Freire, 1994) provided an important perspective in directing this study. Concepts of community development, empowerment education, and praxis—reflection and action—were utilized. Wallerstein and Berstein (1994) have developed further these concepts. They suggest we take a critical look at working with communities

in a respectful manner, assisting them to identify their own needs and solutions referred to as empowerment education, a way for professionals and communities to work together in partnership. Wallerstein & Berstein (1994) outline two key roles for health care professionals working with disenfranchised communities:

> 1) to serve as a resource and help create favourable conditions and opportunities for people to share in community dialogue and change efforts and 2) to engage in the empowerment process as partners, plunging ourselves equally into the learning process. (p. 144)

The study is also based on health promotion theory as outlined in the Ottawa Charter (World Health Organization, 1986). Health promotion is described as "the process of enabling people to increase control over, and to improve, their health" (World Health Organization, 1986, p. 2). Health promotion strategies and characteristics are outlined in Table 1.

In summary, the philosophical foundations to guide this study include transcultural nursing theory (Leininger, 1991), critical social theory and empowerment education (Friere, 1994; Wallerstein & Berstein, 1994) and health promotion theory (World Health Organization, 1986). They provide a basis for both data collection and analysis consistent with Leininger's (1991) proposed naturalistic method of open discovery to describe phenomena based on the views and experiences of participants.

Table 1. Characteristics of health promotion strategies

Strategy	Key Components
Build healthy public policy	▪ Action directed at developing healthy policies at multiple levels inside and outside the domain of health
Create supportive environments	▪ Assessment of the environment and its impact on health ▪ Facilitation of supportive environments to maintain and increase health
Strengthen community action	▪ Empowerment of individuals and communities ▪ Facilitation of community action
Develop personal skills	▪ Support of personal/social health skills ▪ Facilitation of activities to increase a person/community's control over their health
Reorient health services	▪ Partnership between the health system and communities ▪ Increased emphasis on prevention

CHAPTER FOUR—RESEARCH DESIGN AND METHOD

A descriptive, qualitative study was conducted to explore the perspectives of cervical screening in the Sikh community. A qualitative method was chosen for its strengths—"exploration and discovery, context and depth and interpretation" (Morgan, 1998a), p.12). Naturalistic inquiry (Lincoln & Guba, 1985) provides a method to discover multiple realities; research is carried out in the natural setting paying particular attention to context and its influence on the phenomena of study. The researcher became the instrument of data collection. Purposive sampling where "the researcher selects participants for the study on the basis of personal judgement about which ones will be most representative or productive" (Polit & Hungler, 1999, p. 712) was utilized to ensure many potential realities. Inductive analysis, an essential component of naturalistic inquiry was employed to negotiate interpretations between the participant and the researcher (Lincoln & Guba, 1985). Naturalistic inquiry is particularly valuable in studying complex issues when multiple perspectives on a phenomenon are sought.

Respect for participants in the study and minimizing risk was addressed. Ethical approval for the study was obtained from the Conjoint Health Research Ethics Board of the University of Calgary (Appendix B).

Participants

Current recommendations for cervical screening in Alberta state all women aged 18-69 who have ever had sexual intercourse should have a Pap test annually (Alberta Clinical Practice Guidelines Program, 2000). Based on these recommendations, maximum

variation sampling was used to recruit and select Sikh women to participate in the study. Qualitative researchers often apply this strategy to select participants with a wide range of variation (Lincoln & Guba, 1985; Polit & Hungler, 1999). Differences were sought in age groupings (18-69 years), screening practices and length of stay in Canada (< 10 years and 10+ years). Evidence of variance exists in screening behaviours from one age group to another (Snider et al., 1996) and lower rates of screening in more recent immigrants (Goel, 1994). Both screeners and non-screeners were included in my study to access the potentially different perspectives provided by each group.

Phase One—Interviews

Volunteers were recruited using a snowball method (Polit & Hungler, 1999) by taking referrals for potential participants from earlier interviews or other key individuals in the community. Posters (Appendix C), in English and Punjabi, were placed in various locations in the community (*gurdawara*[5], community service agency, public health clinics, breast cancer screening event). They were also distributed to key community contact people. Punjabi radio was used to advertise the study as well.

All women who volunteered for the study were contacted by phone by either the researcher or interpreter. The nature of the study was explained and eligibility established. Informed consent was obtained at the initial interview with the participant. Consent forms were available both in English and Punjabi (Appendix D).

The researcher conducted in-depth interviews in the women's homes at a time

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[5] The temple for Sikh religious ceremonies.

that was convenient for them. A few interviews were also carried out at the *gurdawara* or at the participant's place of work. For some interviews an interpreter was used as the woman spoke little English. Interviews were generally audio taped. If the woman was uncomfortable with audio taping, detailed notes were taken instead to capture the participant's responses. In addition, field notes were written for all interviews to summarize non-verbal communication and context. All English tapes were transcribed verbatim. Punjabi interview tapes were translated and then transcribed in the same manner. Notes from untaped interviews and field notes were also transcribed.

Open-ended questions were developed (Appendix E) using the informal interview technique described by Fetterman (1998). This type of interview is most often applied in ethnographic research that uses "the most natural situation or format for data collection and analysis" (Fetterman, 1998, p. 39). Such interviews employ casual conversation based on research questions. Informal interviews establish rapport, are useful to ascertain what community members think and compare differing perceptions. "Such comparisons help identify shared values in the community—values that inform behaviour" (Fetterman, 1998, p.38). Fetterman (1998) also stresses the importance of the researcher to be holistic, focusing on culture and context in the course of the research.

South Asian women feel most comfortable in sharing stories of their experiences (Bottorff et al., 1998) and the success of an unstructured, conversational type of questioning was evident in interviews I conducted during a graduate nursing practicum directed at assessing Sikh women's health concerns (Oelke, 2000). Establishment of trust

and rapport with participants is important (Rothe, 1993), therefore questions moved from the general to the more specific during interviews.

Phase Two—Focus Groups

Once the interview phase was almost complete, focus groups were carried out to extend and validate findings with a larger group of women. Focus group participants were recruited by a different method from those who participated in the interviews. Two focus groups were organized by a community service agency. The third focus group was recruited through English as a Second Language (ESL) classes at a local college. The focus group organizer contacted all potential focus group participants, the study was explained and agreement to participate was determined. Consent information was reviewed at the beginning of each focus group with consent forms (Appendix D) completed by each participant. Demographic information forms (Appendix F) were also filled out at the beginning of the focus group with the assistance of the facilitator and focus group organizer.

Focus groups were conducted with a skilled Punjabi speaking facilitator and utilized the guiding questions as outlined in Appendix G. The same facilitator conducted all three focus groups. Detailed notes on context and non verbal communication were taken by the researcher while observing focus groups. All focus group tapes were translated and then transcribed verbatim. Field notes were also transcribed.

In addition to responding to the preliminary findings of the interview phase, focus group participants were asked to brainstorm about how resources and services could best

be delivered in their community. Over and above validating data assembled from interviews, focus groups provided an opportunity for triangulation of data collection methods for the study. The aim of triangulation is to gain multiple perspectives on the research question by using a variety of informants, strategies and methods to inform the phenomena being studied (Polit & Hungler, 1999).

Two methods were used at the beginning of the focus group to increase the comfort level of women and to obtain feedback on previous data collected from the interviews. An icebreaker exercise asked women to comment on what was one of the most difficult things for them when they immigrated to Canada. Moving around the circle each woman shared one item. Next, on a flip chart we listed obstacles to cervical cancer screening discussed by women in the interviews conducted previously. The focus group participants then wrote down the top three reasons why they thought women in the Sikh community did not attend for cervical screening. This provided the validation necessary of the data collected earlier.

The appropriateness of focus groups with both sensitive issues and in a cultural community has been explored and supported in the literature. Morgan (1998a) suggests that focus groups can be utilized with sensitive topics if carried out appropriately. Focus groups conducted with older Hispanic women in the United States were very successful because women welcomed the opportunity to discuss similar issues with other women from their community in a safe environment (Saint-Germain, Bassford, & Montano, 1993). Earlier, during a graduate studies practicum, a focus group conducted in this

community was readily accepted by the women in the group (Oelke, 2000).

Ground rules were established at the beginning of the session with particular attention to privacy and confidentiality as recommended by Morgan (1998a). This was especially important due to the small size of the Sikh community in the city; many women were acquainted with each other.

Translation and Interpretation

Consent forms were available both in Punjabi and English (Appendix D). The English consent form was translated into Punjabi by the interpreter and then was back translated by a Punjabi speaking health care professional and reviewed for accuracy. Changes were made as needed. Another Punjabi speaking health care professional reviewed the final consent form.

Several Sikh women reviewed interview and focus group guiding questions to determine their appropriateness in their community. Focus group questions were translated by the facilitator and reviewed by another Punjabi woman for accuracy of translation.

An interpreter was used for interviews with women who did not speak English fluently. During the process of the interviews the interpreter would occasionally provide some context in the situation enriching the data collected. Audio tapes were translated and transcribed in their entirety to ensure none of the information shared by the participant was missed.

A skilled Punjabi speaking moderator was contracted to conduct focus groups.

To maintain consistency the same facilitator was used for each of the three focus groups. Basic training around interpretation and translation was provided both to the interpreter and focus group facilitator.

Methodological Issues

When conducting research in a cultural community potential methodological issues may arise such as trust and rapport. Also of importance is the heterogeneity of the population targeted in the study.

Both Bottoroff et al., (1998) and Choudhry et al., (1998) in their studies of breast health practices of South Asian women were concerned about the data collection techniques used in their studies. Women in this cultural community were very worried about giving the "right" answer and may have biased results. The interpreter, focus group facilitator and myself as researcher needed to be aware of the potential for this action to occur. A comfortable and safe setting was required during interviews and focus groups. Taking time to build trust and rapport in the community was also an important process.

Another concern is the diversity within the South Asian community. This is not a homogeneous population group; cultural and religious values vary affecting health beliefs and practices. Generalizing findings from one population subgroup to another may be difficult. The current study will focus only on one of the cultural/religious groups in the South Asian community. Even though variations exist within the group of Sikh women participants, variation should be less apparent than variations between Sikh women and

other groups in the South Asian community.

Data Analysis

Inductive data analysis as described by Lincoln and Guba (1985) was utilized as a process of making sense of the data. The process of analysis was facilitated with the N5™ software program.

A cyclical process of data analysis followed each interview and focus group. Key points were examined and used to inform the next questions for the interviews/focus groups. Data from each interview or focus group were analyzed for common themes with broad categories and patterns identified. Relationships among the data became apparent throughout the process. When most interviews were completed the data were again re-examined to identify barriers to screening for these Sikh women, which were then presented for validation by focus group participants. Upon the completion of all interviews and focus groups a final round of analysis of the data was initiated. These included refining definitions, examining interrelationships among barriers and participation in screening, systematically comparing and combining similar themes with sub-categories as necessary for each theme noting gaps and duplication. Lincoln and Guba (1985) refer to these processes as categorizing, pattern filling and indexing. Consideration was given to the complexity of the data, particularly the focus group transcripts and notes, as well as the context of the information collected.

Trustworthiness

Member checking (Lincoln & Guba, 1985) was conducted with three of the interview

participants. Findings were provided to two of the participants to obtain their reaction and feedback. Another woman participated in a group interview with the Phase Two data collection team.

Trustworthiness was established by three audits; process, confirmability and dependability (Lincoln & Guba, 1985). During the process audit, a research expert reviewed the initial interview transcript to provide feedback on interview techniques. A second audit for confirmability was conducted by a Punjabi speaking academic to determine the accuracy of translation and transcription of two interviews conducted in Punjabi. Finally, a qualitative research colleague performed a dependability audit of three interview transcripts and one focus group transcript to compare themes that were derived from the data (Appendix H).

Summary

Perspectives on cervical cancer screening of Sikh women were collected using a descriptive study by means of the qualitative method of naturalistic inquiry outlined by Lincoln and Guba (1985). Participants for interviews and focus groups were recruited using a snowball method for a maximum variation sample. Analysis by induction using N5™ and methods used to establish trustworthiness were also presented in this chapter. Findings and discussion will be reviewed in the following chapters.

CHAPTER SIX—FINDINGS AND RESULTS

In this chapter the results of the research study will be presented. These will be organized into three broad categories—methods, participants' demographic information and research findings. To maintain anonymity, initials (pseudonyms) have been used to identify the quotes of women who participated in the study.

Methods

Recruitment

Early in the study, recruitment of participants was slow, despite a number of different promotional strategies utilized to engage women. In an attempt to increase enrolment, I made a presentation about my study to a group of senior women who met weekly in the temple. Several women were recruited from the presentation. In the latter part of the study, more and more women wanted to participate or participants would suggest that the researcher ought to talk to a sister or friend. Women verbalized that they wanted family and friends to learn about this important information too. In general, women in the Sikh community are very keen to learn about their health. In the end, the most successful tool was "word of mouth."

The most difficult group of women to reach were those in their thirties with younger families. They women were busy with a variety of commitments (at home and work) and therefore less available to interview. At one early point in the study, due to the lack of participants particularly in the 20-40 year old age groups, I was concerned that there was a problem with the comfort level of women with myself, an outside researcher.

Several participants were asked about this during an interview. "It is not easy for us to talk to these people but if you're talking to them they might like be more receptive to you." G.M. Int005, Text Unit 91. Another participant said:

> I think because you're outside the community there is more trust. If you're inside the community and you say something, well you're not sure where it's going to go. It's like you're outside of the community so it is going to stay outside... Because it is such a personal situation, they actually probably should be more comfortable talking to you about it...I do know that for women of my generation, [they] we would be much more likely to speak to you than someone from our own community." N.G. Int004, Text Units 58-60, 62.

An outside person allowed the women more freedom in discussing private issues and potentially increasing the confidentiality of information shared.

One of the women thought the difficulty encountered in recruiting younger women in their twenties and thirties may be related to their desire to refrain from discussing this type of topic. These women, in particular, would be the ones trying to please family, in-laws, and other community members and not wanting to cross culturally determined lines. This same woman stated she needed to be careful as well. "I can't go against my parents' wishes." G.M. Int005, Text Unit 51. Her reference to parents included both her biological parents and in-laws, particularly her mother-in-law.

The researcher also found it was important to participate in social activities in the community to get to know community members and build a relationship. Several social

events were attended that allowed an opportunity for greater exposure to the women of the community. Spending time at the *gurdawara* was also effective; being in the temple was somewhat of an event for community members—men and women alike were curious as to why I was there. "A gentleman (senior) came to talk to me and was trying to teach me a few Punjabi words. [I] also communicated with a few women socially in broken English." Field Notes, November 1, 2001. The researcher had the sense that if she sat with these women and assisted in peeling vegetables, further rapport would be gained. The many times the researcher did visit the *gurdawara,* having tea *(chai)* was an important ritual. It assisted in being further immersed in the culture and in promoting the study to other community members. "Women were very interested in what was going on—we talked about the study and recruited another person for an interview next week." Field Notes, November 1, 2001. The next week the woman did not show for the interview, despite having the interpreter follow-up with her the day before. But there always seemed like there was someone else who was willing to talk to us and an interview with another woman was conducted. Flexibility of the researcher and interpreter was very necessary in recruiting participants in the study.

Despite the challenges associated with cross-cultural research, I was able to successfully recruit women with the assistance of key community members. As a result I was able to gather data from 13 women in individual and group interviews and a total of 40 women through 3 focus groups. Women were generally open about their experiences and perspectives on cervical cancer screening. They wanted the opportunity to

participate and share their views as well as gain new health information important for their well being.

Data Collection and Analysis

Data for the study were collected over the period of approximately one year. Interviews and focus groups were conducted in a variety of settings such as women's homes, the *gurdawara* and the workplace. When completing the data collection, I was careful to dress appropriately as specified by cultural norms and wore a head covering when at the *gurdawara.*

The initial phase of the study included 11 in-depth interviews with Sikh women to collect data on their perceptions on cervical screening. Interviews were approximately one hour in length. Two women participated in a second interview for member checking and to extend initial findings. With the exception of two interviews where participants declined to be taped, the nine other interviews were audio taped. Interviews were conducted until data saturation occurred. Experts agree that this is an appropriate number of participants for this type of study (Polit and Hungler, 1999).

In phase two of the study, three focus groups were completed with audio taping, one more than originally planned. The third focus group was conducted because the transcriptionist lost a significant portion of the data from the second focus group during translation and transcription. In consultation with my faculty advisor and thesis committee, to resolve this situation, an independent facilitator was hired to conduct a group interview with the original focus group organizer, facilitator and the researcher in

an attempt to recapture the data that were lost. This interview allowed me to potentially recapture the lost data, but also to validate information collected during previous interviews and the focus group. New data from these participants was also included and used in analysis. As a significant amount of time had transpired I decided to conduct an additional focus group with Sikh women in the community.

A total of 40 women participated in the focus groups. Two groups were very large with 16 and 18 participants each. The women were very enthusiastic to participate and did not want to miss an opportunity to give and receive information. Although less than ideal (Morgan, 1998b), and somewhat difficult to manage, the facilitator and I decided to proceed as it was difficult to turn away volunteers. The challenges of a large focus group were managed in several ways. The facilitator made a conscious effort to allow everyone an opportunity to speak. We also utilized the support of the two women who organized the separate focus groups in again ensuring the participation of all who had attended.

Participants' Demographic Information

Demographic information was collected for both women interviewed and those who participated in focus groups (n=53). Women ranged in age from 21 to 65+ years. Most of the women were married, a few were single and another divorced. Although I did not specifically ask about arranged marriages, for most of the women who participated in the study this was the case. Only 13 women lived in a household with extended family. Others lived in a nuclear family or with another relative. Data on living

arrangements were missing for 5 participants. Only one participant was born in Canada. Other women came from India and immigrated to Canada anywhere from 6 months to 32 years ago. Most of the women had been here less than 15 years. All participants spoke Punjabi with a range in English speaking ability from minimal to very good. Participants' education levels were wide spread ranging from Grade 9 to university education in India. Several had received post-secondary education in Canada. A number of the women were employed full-time or part-time while others were seeking employment, homemakers or students. Many worked or had been employed in factory or service industry occupations. Participants were also asked about income levels. Only a small number of women answered this question, reporting incomes ranging from $16,000-$80,000 or more (personal or family) per annum. Many had an income of $25,000 or less per year.

Research Findings

Two overarching themes were identified in the process of data analysis. Women referred frequently to the concepts of "inside" and "outside" and their influence on cervical cancer screening by Sikh women. These findings are presented in the first part of this section and address the research question, "What are Sikh women's perspectives on cervical cancer screening and the Pap test?" Influences on women's screening behaviour relate to those that are inside their own bodies, their inside personal sphere of influence, those that are totally outside over which they have little control and many influences that lie in between the two extremes causing much tension in attending for

cervical cancer screening. An additional layer of inside/outside exists when health care professionals must reach Sikh women to bring them inside into the health care system to obtain a Pap test. This relationship will not be addressed directly in this study, but will be discussed in light of obstacles within the health care system for Sikh women in obtaining screening.

The second theme is that "it is good if everyone knows." Sikh women believe that information on cervical cancer screening was important knowledge for others in their community. The second part of this section includes findings about how Sikh women would like cervical cancer screening resources and services delivered in their urban community, addressing the second research question.

"Inside" Our Bodies

For Sikh women the cervix exists in an unseen or unknown part of the body. One woman talked about the cervix and the Pap test in this way:

> ...heart problems are different, brain problems are different, some things you can see it, some you cannot see. So it is for something you cannot see. A problem or anything inside, anything like that. J.G. Int007, Text Unit 86.

Similar references were made to "inside" when other women were asked about the Pap test.

"A Lot of the Time No One Knows"

Outside knowledge of the Pap test is unknown to these women and often times not available to them. Not knowing keeps them from participating in outside screening

activities therefore not fully participating in the outside world of Canadian society.

"You know, mostly our Indian women do not have the Pap test" D.M. Int011, Text Unit 195. Several study participants stated that up to 75% of the women in their community were not having regular Pap tests or had never had a Pap test. During the study recruitment phase, I made a short presentation about the study to a group of approximately 20 senior women. Only one woman knew about the Pap test and she had been previously employed as a health care worker. Fewer than half of the 13 women interviewed face-to-face were regular screeners and one had never had a Pap test. Others reported being screened from time to time with prenatal and postnatal visits or if they had a female health problem. Although focus group participants were not asked about their personal screening behaviours it was evident that many of them were not regular screeners as they were not aware of the Pap test. "I did not know anything about it till I came here [the focus group] and I have never had it done." Participant, FG002, Text Unit 270. Another participant states, "Not yet, I hadn't heard anything. Nobody talks about this, women don't tell each other." K.B. Int002, Text Unit 85. Others were aware of the test but did not know what it was for. Some of the women had learned about cervical cancer screening only in the last few years. This was not necessarily related to length of time in Canada. Participants often stated that they knew about cancer but were not aware that one could have cancer of the cervix. Many were not aware of what the cervix was or where it was situated in their body.

Women had varying knowledge of Pap tests, but one consistent influence

appeared to be age. Older women tended to know the least about the Pap test. Women also thought new immigrants were less likely to know about cervical cancer screening, as this preventative health test is generally not practiced in India. Although education was cited by some as making a difference this may not always be the case.

> I'm well educated but still I didn't know about these things. It's not about being educated. I saw the doctor when I was pregnant regularly and for my six week check-up but not otherwise. I asked her at that time about a mammogram but not about Pap tests. K.S. Int009, Text Units 27-29.

Young women who grew up in Canada were seen to have more knowledge about the Pap test. This information was most often obtained at school through different presentations on various sexual health issues. It is important to note that even though they were aware of the Pap test they may not necessarily have accurate information as to why it needed to be done.

Some of the women did not realize it was important to be screened for cervical cancer on a yearly basis. "I had it done and then I felt relaxed and I do not think about going again." V.B. Int010, Text Unit 124. Women often felt that if they had it done once and it was normal they did not need to go back.

Two of the 13 women interviewed knew the Pap test was for cancer screening. Even though some of the women had been screened in the past most were not aware of the reasons for the Pap test.

> My sister-in-law had it done and then she told me that the doctor had told her

> that after each baby you should have the Pap test done. Otherwise there may be something left inside and that could be harmful. V.B. Int010, Text Unit 114-115.

Because little information is given to women about the Pap test they become confused about the reasons why the test should be completed or the importance of it.

> My main concern was that I was having these pains and I went to the doctor and he said that he was going to check me and see what was wrong inside. That is when he did the Pap test and when I asked him if everything was alright, he said yes it was and that I should do exercise. Although he did the test himself, he did not tell me the reason for it. V.B. Int010, Text Unit 127.

Several women mentioned that the Pap test was used to screen for sexually transmitted diseases (STDs). They also thought the test was used to detect potential problems from the birth control pill.

In addition to knowledge, a lack of focus on prevention was identified to influence screening among women in the Sikh community. This is discussed in the following paragraphs.

"My Body is Perfect, Why Should I Go To the Doctor?"

Women in the Sikh community believe that seeking health care in the absence of symptoms is not necessary and sometimes inappropriate. This lack of focus on prevention causes them to remain inside and not readily participate in screening.

"[For] so many years they have survived without these tests. Nothing has happened to them." Participant, FG001, Text Units 294-295. "I think that is a trend. If

you are sick or something is a problem then you only [see the doctor]." M.K. Int008, Text Unit 40. Community members generally do not see the doctor for regular screening, such as having your blood pressure checked, and the like.

> ...you only have to go to the physician when you have [a] certain problem. If you're fine then you're wasting your time going to a physician. They don't have importance in regular check-ups. M.K. Int008, Text Unit 67.

Women generally see the doctor regularly for pregnancy care. This has become an accepted practice in this urban Sikh community. The standard six-week postnatal check-up may or may not be completed.

Women suggested several reasons why community women were not likely to participate in cervical cancer screening. The cost of health care in India prohibited regular check-ups. Physicians generally do not prescribe screening tests, as they are quite costly. Women may think that screening tests in Canada may also cost them money personally or are not aware of the screening tests as they did not participate in these tests in India.

The family, as presented in the following section, may also influence obtaining care from a physician. Being sick and having to see a doctor could cause many problems in the family and larger community. So as much as possible women do not see the doctor. They go only when it is absolutely necessary, when they can no longer carry on their day-to-day routines including working and caring for the family.

"Sacrifice for the Family"

Family structure and relationships may influence a Sikh woman's ability to get to the outside, to attend for cervical screening. The Sikh woman's role within the family and her family obligations make it difficult to see a physician for screening. Her outside family obligations keep her inside making it difficult to have a Pap test completed.

Arranged marriages are very common in the Sikh community. One of the participants stated that she thought 98% of marriages were arranged, although this practice is changing. Many arranged partners, whether husbands or wives, also find themselves as new immigrants to Canada. Marriage partners are often sought in India or those in India are looking for a marriage arrangement in Canada.

Traditionally the custom is for the new wife to leave her own family. She will go to live with her husband and his extended family including parents, brothers and their families. It is interesting to note that most of the participants did not live in an extended family situation.

Male and elderly community members tend to dominate the Sikh community.

"It is a male dominated society, and we accept that. You have to accept that." G.M. Int005, Text Unit 45. "...men have more say in the [Sikh] community; woman is a second-class citizen [in] somewhat." M.K. Int008, Text Unit 41. Referring to the wife in a marriage relationship, a participant describes the husband's way of thinking, "that's their mindset, that because they [men] think we have to protect their property [women]." S.T. GrInt001, Text Unit 397.

About elderly community members, a woman shares this conversation.

> Like its...their egos are hurt. They feel we are not accepted[ing] of them because we are their children. What they think is that if we have come to Canada, we have come to a different society, like we are not obedient to them. It hurts their feelings if we do not accept what they say...all young people are actually dominated by the elderly of our society. We have to accept what they say. In my case, also, I can't go against my parents' wishes. I can do lots of things because I have been raised out of the community but still I have to answer to certain things. G.M. Int.005, Text Units 48-51.

Within the family the "husband has financial control and power." S.T. GrInt001, Text Unit 450 and the mother-in-law is referred to as the "domestic goddess. That's what you call her. So she has control over the house." S.T. GrInt001, Text Units 450-453.

> ...especially [the] mother-in-law [is] a very important figure in our society and you have to ask the mom-in-law for this and that because if by certain things that a relation gets bad then it is very, very difficult to repair that relation...A very delicate relation and if [it] goes, by one click it goes, it is very difficult to repair. G.M. Int.005, Text Units 52, 54.

Relationships between the mother-in-law and daughter-in-law varied depending on the individuals and families. Some relationships are open and respectful of each other while in others the mother-in-law is a very dominating figure. "The mother-in-law has control over the family...what you [daughter-in-law] do and what time of day you go."

S.T. GrInt001, Text Units 448, 453.

The children, the husband, the in-laws, household duties, cultural obligations and working outside the home come before a woman's own needs. Women are encouraged not to complain and ensure the care and happiness of everyone else. Because of the society's structure and obligations women put the needs of others first. Sikh women do not give priority to their health.

> You are fine and you are working everyday, your regular routine is going and your body is fine. It is okay, there is nothing wrong with me. I don't need to go to the doctor. J.G. Int007B, Text Unit 48.

Another woman states:

> ...women tend to ignore things and [say that] put her needs on the back burner. Family comes first, then husband comes first or in-laws or cultural [things]. All these come first and then you come in the end as the last thing...." M.K. Int008, Text Unit 54.

"Our men do not allow them, even we do not bother. We just take Tylenol if we have a headache or if the arm is hurting or they cannot even walk." Participant, FG002, Text Units 342-343. Pain and suffering were considered to be good for a woman. As a woman, "my health...it's not important." S.T. GrInt001, Text Unit 886.

For many of these women time is also a factor, especially for health promotion practices that do not relate to overt or experienced symptoms. Women have considerable responsibilities within the family and community. Very often they work outside the

home and continue to have full responsibility for the children, other extended family and day-to-day household chores. The role of the woman in the household is taking care of her family.

> She gives priority to taking care of her children at home...If it is something regarding our meals or regarding the children it is the female member you have to talk to, then the male member does not have to do anything. G.M. Int.005, Text Unit 127.

Permission for medical appointments may be required from a woman's husband, another male family member or the mother-in-law. One participant was asked if this might influence whether a woman could attend a doctor's office for a check-up. She stated, "I can't think that anyone wouldn't allow a daughter to go, if it was for health reasons, if there was a problem." A.P. Int.006, Text Unit 65. I then asked her about screening and a check-up but unfortunately she didn't answer the question. Another woman was not allowed by her husband and his family to see a doctor for her six-week postnatal check-up. Yet, a different woman stated, "The family will not say anything. Why should they say anything because it's to our own benefit?" K.B. Int.002, Text Unit 151. For some women their families were a positive influence in being screened for cervical cancer. They were encouraged to go to see the doctor for an annual physical by family members. Daughters were particularly influential with their mothers if they lived close by.

"Our Culture is About Honour and Morals"

Cervical cancer screening is and continues to be a closed topic between women in the community. Topics such as these are kept inside, to maintain outside reputations of the woman and her family within their cultural community. "Nobody talks about this, women don't tell each other." K.B. Int002, Text Unit 85. All participants, regardless of age or how long they had been in Canada agreed that talking about the Pap test is a very private issue in the community, therefore there is little or no discussion of the topic.

> The community is very hush, private about such things, these things are personal and you keep private and you don't talk about [them], you don't openly discuss such things. N.G. Int004, Text Unit 45.

Lack of knowledge appeared to be closely connected to the limited conversation among Sikh women of female reproductive health concerns, particularly those linked with sexuality, including Pap testing.

> Maybe that's why people don't know about it because it's just something that you're very quiet about and private and you just don't talk about [it]. How do you discuss something when nobody knows that it should be done? N.G. Int004, Text Units 46-47.

Intergenerational conversation between mothers and daughters and mothers-in-law and daughters-in-law was minimal.

> I think at that time the mothers did not have any idea about cancer and all that. Like my mom, she live[d] in India and she did not know anything about it so how

is she going to tell us.... K.R. Int011, Text Unit 268.

Many of these women do not know about the disease and the appropriate screening test. Therefore they are unable to pass along important information to daughters, daughters-in-law and other women in the community.

> It is the lack of knowledge and the shyness, I think both go hand in hand, cause maybe shyness leads to lack knowledge and lack of knowledge like goes to the shyness, it is a vicious circle. G.M. Int.005, Text Unit 137.

This woman goes on to state:

> ...these things are very, very, very private things, we are not suppose to discuss these things with different people.... because they think we are doing something wrong when you talk about all these things. It is a shame on you to be talking about these things in public. This is what they normally think. You can talk about all these things when you are sexually active. You can't talk about these things before that. If you do talk about these things someone think[s], oh, what is wrong with you? That is what they say and you don't want people to have wrong thoughts so you keep your mouth shut. G.M. Int005, Combined Text Units 22, 47, 153.

Study participants often talked about the Pap test and cervical cancer in terms of sexuality therefore making it an inappropriate topic for discussion. "...actually I was not allowed to talk about sex, and this is all about having babies or inner parts of [a] woman. That is not appropriate." M.K. Int008, Text Unit 79. Yet another participant stated that it

was not that discussion of the topic was forbidden but rather women chose not to discuss it because of the potential consequences of doing so. This participant in particular had great difficulty in discussing the topic during the interview, often not knowing what words to use to describe the Pap test and what it was for. "But if I say this, what will people think, they don't want [to] expose themselves at all...The risk, oh, you're the bad one." J.G. Int007, Text Units 254, 256. When asked if it had to do with a woman's reputation, she stated, "I would think so. Being a woman, that's what they think, I'm a good one. I'm not talking about the bad stuff." J.G. Int007B, Text Unit 67. Gossip within the community was an issue brought up by one of the focus group participants. If she discussed an issue such as cervical screening with another member of this Sikh community everyone would know about it.

"Female issues are completely different. You cannot share with the family or with everybody you know." J.G. Int007, Text Unit 262. She goes on to say that women may discuss these types of things, particularly if they have a problem, with a close friend or perhaps their mother or sister. Finding privacy for a conversation in the household can be difficult.

> No it is not like you can sit down and talk to someone, especially in the family or like you know, the brother is coming, or the brother is coming there, father shouldn't know this and father shouldn't know that or the brother shouldn't know this. J.G. Int007, Text Unit 260.

This type of topic is not discussed with other family members. It is not acceptable to

have a conversation about any topic with a brother-in-law in the family; you have to keep a certain distance from your male relatives. "...that is taught to us when we get married. We are told we have to keep a distance...." G.M. Int005, Text Unit 77.

Protection of family honour in the Sikh community is apparent in preserving normalcy when a woman is ill. For Sikh women, it is essential to paint a picture that there is nothing wrong. If you can work then you are fine, or if there is something wrong then it is critical to continue to work to preserve the façade that all is well. "If you're sick, they'll think, what's wrong?" Participant, GrInt001, Text Unit, 701. "If they are sick, they still have to look healthy, because people will find out." Participant, GrInt001, Text Unit, 695. It was felt that some women might hide their disease, as there may be no money for drugs, although some of these same women would choose to spend money on something else like a new outfit to attend a party. "They have to look good....at any cost." D.M. GrInt001, Text Unit 695.

Visiting a doctor can lead to concerns for women and their families, even for such things as an annual check-up. If someone sees a woman from the community going to the doctor, then there must be something wrong. For the woman who needs transportation to the appointment or assistance for interpretation, someone will find out that she has been to the doctor, which must mean that she is ill. Letting others know that you are ill is to be avoided if at all possible.

The maintenance of status is also apparent in the community around financial and material possessions. "In our community...we believe in materialistic stuff...." S.T.

GrInt001, Text Unit 731. "If they have money they are happy. That is the key...India is a showoff...like reputation, status and class." M.K. Int008, Text Unit 168, 178. Community members may have several jobs so they can own property and accumulate possessions to portray a certain picture in the community. Women were concerned about the costs of medicines that may potentially be needed if a problem were detected with the Pap test. Other potential costs to seeing the doctor for Pap screening were also mentioned; such as transportation costs, having to take time off work without pay or a family member having to take time off work. Many of the participants in one of the focus groups felt that for these various financial reasons women would choose not to see the doctor in the first place rather than face the possibility that financial resources may be needed, despite the fact that there is no charge for the Pap test. If it was not a life and death situation then why should they spend the money on it?

Status among Sikh community members was also evident in one of the focus groups where one of the participants referred to the lack of knowledge and awareness of the women, "especially on this side." Participant, FG001, Text Unit 194. The translator and the facilitator felt that she was referring to a particular neighbourhood where many of the Sikh community reside.

Another layer of challenges for Sikh women in cervical cancer screening was identified by women. These include various provider issues as outlined in the following section.

Provider Issues

The health system and its structure add further layers of challenges for Sikh women to move to the outside and obtain cervical cancer screening. Providers issues were of particular concern.

"Doctors Never Told Us"

Women from the Sikh community are not made aware of the Pap test and its importance in cervical cancer screening. Participants feel their own family physicians are not telling them. They may see the doctor for a problem here or there but are seldom told to come for an annual physical exam or Pap test. One participant was somewhat angry as to why women are never told about this. "Why the women do not know about this? I feel this is the responsibility of the doctors." V.B. Int.010, Text Unit 75. A focus group participant states, "Family doctors never say anything." Participant, FG002, Text Unit 290 and another participant from the same group counters by saying, "They only send you when the ladies have ... problems. They don't even tell you that there are such facilities." Participant, FG002, Text Units 294-295.

"A Lady Doctor Is Better For Sure"

There were differences in opinion about the gender of the physician among participants. Some of the women felt that the most important was a qualified and good doctor. Nevertheless, most of the participants felt more comfortable with a female provider and if given a choice community women would choose a female physician. "...they prefer a female doctor." G.M. Int.005B, Text Unit 57. The participant goes on

to say that availability sometimes determines who they see and she feels that the gender issue is changing somewhat but "...they are not 100% happy with going for, not for private problems." G.M. Int.005B, Text Unit 139.

> Especially if it is a body check-up, if he is from our own community it is alright if there is fever...I will go to the family doctor for that but if it is anything else I do not feel comfortable. K.R. Int.011, Text Units 307, 309.

Privacy and embarrassment issues were often cited as concerns for women seeing a male physician.

Sikh women have difficulty asking their physicians questions, especially asking about the Pap test. One woman speaks of her mother:

> She goes to an Indian doctor, a Punjabi family doctor. How is she going to ask him? The male doctor! They will never ask even a female doctor. V.B. Int.010, Text Units 65-67.

"...they don't ask questions to [the] doctor because that is not acceptable, that is how you [are] raised how I [was] raised." M.K. Int.008, Text Unit 106.

Many of the Sikh women who have immigrated to Canada often come from rural communities where they are very accustomed to having midwives or female health workers provide health care services. One of the participants expressed how in India when a baby is delivered and no female health care provider is available that the male doctor or nurse will bring a lady with him.

> He can stay outside and explain everything to her, do this now, do that now.

> Yes, I saw it all when my sister-in-law delivered my nephew. He stood outside and the lady delivered the baby. K.R. Int.011, Text Units 403, 405.

Several participants mentioned the concerns of men in the community when a male physician attended their wife. Although this was not considered to be a concern for all women this may be an issue for some as shown in the following quote:

> Even the male members of society, they don't want these ladies to go to the male physicians because that is also improper. They don't want them to go to the male physicians and get all these tests done. You have to really get their permission, you have to really convince them that this is important and then they will let you go. G.M. Int.005, Text Unit 43.

The husband will often then attend the appointment, speaking for his wife as well. Men also feel more comfortable with female physicians as they are seen to have more expertise in female health issues.

Sikh women prefer a female doctor if given a choice. Participants talked about certain situations where there may not be a choice in the physician such as pregnancy or serious medical conditions. "They will never go to a male doctor unless of course they are in pain and think they have got cancer and are going to die and there is no other option." Participant, FG001, Text Unit 195. Attending for screening such as the Pap test is a choice and therefore women may just choose not to go as it is difficult to access an appropriate provider. "If it is a female, they may feel more comfortable. [If] it is a male, they may say, like forget it." J.G. Int.007B, Text Unit 82.

First Language Physician

Language is a concern for many women. Most of the women suggested that a female, first language physician is the desire of many of the women in the community. "...they want to go to their physician, their own community people and...they want to speak the language." G.M. Int.005, Text Unit 114. They may not be able to speak English at all or not well enough to use a mainstream physician without an interpreter. Using an interpreter for such private health concerns can cause problems within the family or community. Access to a first language, female physician is difficult as there are only one or two such physicians practising in this community, servicing a large Sikh population.

Insider/Outsider Physician

Women in the Sikh community vacillate between whether an Indian physician is better or one from outside of the community. It's "the whole trust issue and having someone form your own community, is that a good thing or not?" N.G. Int004, Text Unit 55. Women are concerned about trust and confidentiality. Many do not feel truly at ease that their information will be held in confidence within the Sikh community. They are also uncomfortable when they see doctor at a social function. "Not only that but they may meet the doctor at a social gathering and then the relationship changes and they become friends. It is not the same then." Participant, FG002, Text Units 303-304. Participants describe this Sikh community as a small, close knit community where everyone knows, or knows, of one another.

Some of the women are also concerned about the standard of care that they receive from their own Indian doctors. "... I wouldn't like to go to our community doctor because they do not give us the treatment and the information that is our right." V.B. Int.010, Text Units 92-93. "Another thing the Punjabi doctors do not do the check-ups." K.R. Int.011, Text Unit 464. Many of the women commented on how very busy Punjabi doctors' offices were. They felt the doctors did not take time with them and this was suggested as a reason why they did not receive information on Pap tests or had them done.

Punjabi doctors also seem to be hesitant to talk about female health issues and the recommendation of required screening tests. When asked about this, one woman explained:

> Yes, yes, they feel embarrassed; cancer is a very serious disease. They should be telling us all about it...the doctors don't like to tell the patients because I don't know why, because I think they respect us. K.R. Int.011, Text Units 111, 461.

Another woman comments on how her family physician, a woman from the South Asian community, after more than twenty five years is still embarrassed to talk to her about her pregnancies.

Access To A Physician

Many women were also concerned about the inability to find a family physician, particularly in the Sikh community.

> ...as far as I know there is only one [female] doctor over there. All of them, they prefer to go into their own community doctor and there is a big shortage of doctors over there. G.M. Int.005, Text Unit 114

Women felt this was a very important issue to address. It was essential to tell women about the Pap test but if they could not find a family doctor to go to they still would not be able to get the test done. "So we really need nurses or Indian female doctors." Participant, FG001, Text Unit 197.

Apparent throughout the findings is the theme of inside/outside—where Sikh women are faced with numerous challenges to move "outside" to Canadian society in order to participate in cervical cancer screening. Within these challenges also lie opportunities to reach women, to raise their awareness and increase their involvement in screening. Data were collected on strategies to reach women in this urban Sikh community with important health information and service.

"It Is Good if Everybody Knows"

It became apparent throughout the study that many of the women were very interested in this topic as more and more women wanted to participate in the interviews and focus groups. Interview participants would say, "you should talk to my sister or my friend, they need to hear about this information." Focus groups 2 and 3 included large numbers of women because they wanted to participate and hear the information. One of the interview participants, who also organized one of the focus groups, summed it up by saying:

> ... because in our community we don't do these types of discussions, women have curiosity, they want to know ... They want to learn, they want to get better so any opportunities they get of sharing or getting to know stuff, they want to take it. S.T. GrInt001, Text Unit 82.

All participants expressed opinions that women needed to be informed of the Pap test, its advantages, risks of not being screened and the importance of regular annual screening. "Suggest to them and tell them what the advantages [are] of getting the test done and what are the dangers if you don't." Participant, FG002, Text Unit 207.

Strategies To Reach Women

The challenges of providing culturally appropriate, accessible services to women in the Sikh community are numerous. A variety of different ways were recommended to reach women with this important information. These ideas have been organized into the following categories—media, small group education, one-to-one education, first language resource materials, provider strategies and other recommendations.

Media.

Various ethno-specific media with programming in Punjabi were strongly recommended by focus group participants as important, appropriate avenues to reach women in the Sikh community. These media include Punjabi television, radio, newspapers and magazines particularly two of the magazines that are available free of charge to the Sikh community. Media initiatives should include both advertising, particularly if special clinics were held, and information. Several women mentioned that

watching Indian movies on TV was a very popular activity among Sikh community members, therefore information could be presented before, during and after movies are aired. The development of a first language video with information on cervical cancer screening was also suggested but participants realized that the funding required for such an initiative might be difficult to secure.

Small group education.

Women suggested that group education sessions, referred to as "Education Camps" be held at the *gurdawara* and other facilities in the Sikh community to inform women of the need and importance of cervical cancer screening. These should be accompanied by simultaneous Pap screening. With transportation and time being an issue these clinics could provide women an opportunity for same day screening. "They will get fresh information about avoiding the cancer and the best thing is to catch them on the same day and perform the test." Participant, FG001, Text Unit 313.

Women suggest that these sessions would need to be advertised by various means in the Sikh community.

> For example if it was announced in the *gurdawara* that there were tests being carried out and that there are nurses and doctors downstairs and you can talk to them, then that would be the best way to reach these ladies, young girls and older women as well. Participant, FG001, Text Units 183-184.

Word-of mouth.

"In our community it is everybody's business, you tell one person something,

everybody will be informed...they learn from the people." G.G. Int011, Text Unit 280. Women recommended the use of the existing informal network of friends and family to get information to women in the Sikh community. Women will generally seek information from a friend first. Information from family members will then follow depending on the relationship between these individuals. In some cases a friend may also be a close relative. Many times during the interviews women spoke about how they may have heard about Pap screening from a friend, a sister, or how they told their sister, sister-in-law about the importance of screening. One of the participants explained it well by saying:

> Yes even if one out of a hundred ladies takes the brochure and reads it she can inform all her friends. Even if there are ladies who do not want to pick up any, the others can inform them like my sister told me all about it and I told my sister-in-law, we are three sisters and then I told my friends. I think all the community can learn.... K.R. Int011, Text Unit 277.

"If we tell another friend and explain everything to her, she will inform a few more and if they have not had it done they will be aware of the advantages of this test" S.P. Int011, Text Unit 285. Another participant spoke about her own personal situation where she was diagnosed with a fibroid tumour and had a hysterectomy. This frightened her and she realized the importance of regular check-ups. She now shares her story with her female friends and relatives emphasizing that regular physical examinations are essential to their health.

First language resource materials.

Most of the women in both the interviews and focus groups agreed that written materials with information on cervical cancer screening were necessary, especially in their own Punjabi language. Other participants suggested that English materials were also important, as many women may be able to read English better than they can actually speak it. There were also various ideas as to where this information should be placed. Doctor's offices, whether Punjabi speaking or other physicians who served Punjabi speaking clients, were felt to be important locations by all participants. Other ideas included the *gurdawara*, beauty salons and Indian stores.

Provider strategies.

Provider issues have been previously discussed in this report and will not be repeated at this time. It is important to note that women felt issues such as female providers, recommendations for screening by the doctor, language barriers and the lack of family doctors needed to be addressed. One of the participants stated that it was important to work with family physicians, as women will listen to this message, "because it comes from the physician...they look up to the doctor." D.M., GrInt001, Text Unit 594. One suggestion was to provide Punjabi and English pamphlets to doctors' offices. Participants were asked about the potential of trained nurses to conduct cervical cancer screening for women in their community. One woman states, " ...moreover we don't want to go to the doctors, we want to see the nurses." K.B., Int002, Text Unit 87. Many of the women thought this was a good approach; they would support such an initiative

and attend nurse-managed clinics to obtain regular Pap testing. The preference would be that the nurse would be able to speak their language, where other women stated that a nurse not able to speak the language could work in partnership with a Punjabi speaking male doctor. In the past there have been some concerns around the acceptance of the nursing profession among community members. In India, nurses are not always highly respected as they generally function under the direction of a physician and do much of the so-called "dirty work." There was a sense from the participants that nurses in Canada are more widely respected and that many Sikh women felt comfortable with nurses. When speaking about nurses they speak of the group as being female which may account for some of the comfort with this group of health care professionals.

Other strategies.

There was disagreement among participants as to using the *gurdawara* as a contact point for delivering information to the women attending. Even so, most of the women felt that this was an important place to offer women information and screening as many women attend religious ceremonies or social events at the temple, particularly on the weekends. Displays in the *gurdawara*, information sessions and announcements to advertise presentations were suggested as appropriate ways to reach the women in their community.

Most of the women also suggested the *Tiaan Mela*[6], a woman's festival, as a

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[6] Annual Women's Festival in the Sikh community that consists of a variety of activities such as music, dancing and cultural foods.

very appropriate venue for both information and a short presentation. The celebration takes place once a year with only women present to dance, shop and eat traditional foods. These festivals are well attended and accepted by all community members offering an excellent opportunity to reach many women from the Sikh community with health information.

Permission

Several women were asked about obtaining permission to talk about cervical cancer screening in the community. As the Sikh community is generally a male and elderly dominated society, then permission may be necessary to speak about an issue that is not normally discussed or is forbidden to talk about. It is summed up rather nicely in the following quote:

> If this is something for our health and they want to talk about it, something for our community then we can do it. In the community you just go and talk to them [community leaders], they can pass the message [to women]—this is for your health, and what's going on. [Then the] ladies can get together and they can talk. J.G. Int007, Text Unit 216.

Another participant suggested one way is to talk to older women first, as they have some control over the women in the community. If they consider it important then this can be helpful in reaching the community in general.

Sensitivity

Some of the women were concerned about privacy of the issue and bringing it

into the temple while others were apprehensive that men are there as well. "They always put this fear into women. Maybe if we go and sit with the women and ask the men to leave and then announce it I am sure the...ladies will come." Participant, FG001, Text Units 335-336. These same women also discussed the mammography screening that was conducted in the temple in previous years and how successful this "camp" was. Women were provided with breast health information and screening simultaneously. In the past year diabetic screening has also been conducted at the *gurdawara.*

Summary

The goal for women in this Sikh community was to move from the inside to the outside to obtain cervical cancer screening. They talked about how knowledge, lack of focus on prevention, family and community influences, and provider issues created barriers both within and outside the community, influencing Pap testing participation. Furthermore, they made several suggestions for strategies to reach Sikh women to increase awareness and decrease obstacles, to move women from the inside to the outside. In the next chapter these findings are discussed in light of the literature on the topic and the context of Sikh women's lives.

CHAPTER SEVEN—DISCUSSION OF FINDINGS

Due to lack of participation in cervical screening, the threat of cervical cancer for Sikh women appears to be hidden both in the woman's body and in the Sikh community itself. Layers of challenges were uncovered impacting Sikh women's involvement in screening. Participants frequently referred to the concepts of inside/outside during interviews and focus groups. As pointed out by the auditor, there was a real sense of having to maneuver and negotiate many obstacles to make it to the "outside," to be part of Canadian society, in this case to be screened for cervical cancer. But there is a tension for these women. As individuals they have obstacles to overcome in seeking out screening (e.g. lack of knowledge and limited focus on prevention). Family and cultural influences also cause tension regarding participation in screening.

Inside/outside is generally defined as belonging to a group (Bartunek & Louis, 1996). Those who belong to the group (insiders) possess knowledge or traits specific to that group, share experience or unique interests whereas outsiders lack this knowledge and shared context. Contrary to this common view these Sikh women, while insiders to their own community, desire also to be accepted into the larger outside Canadian society.

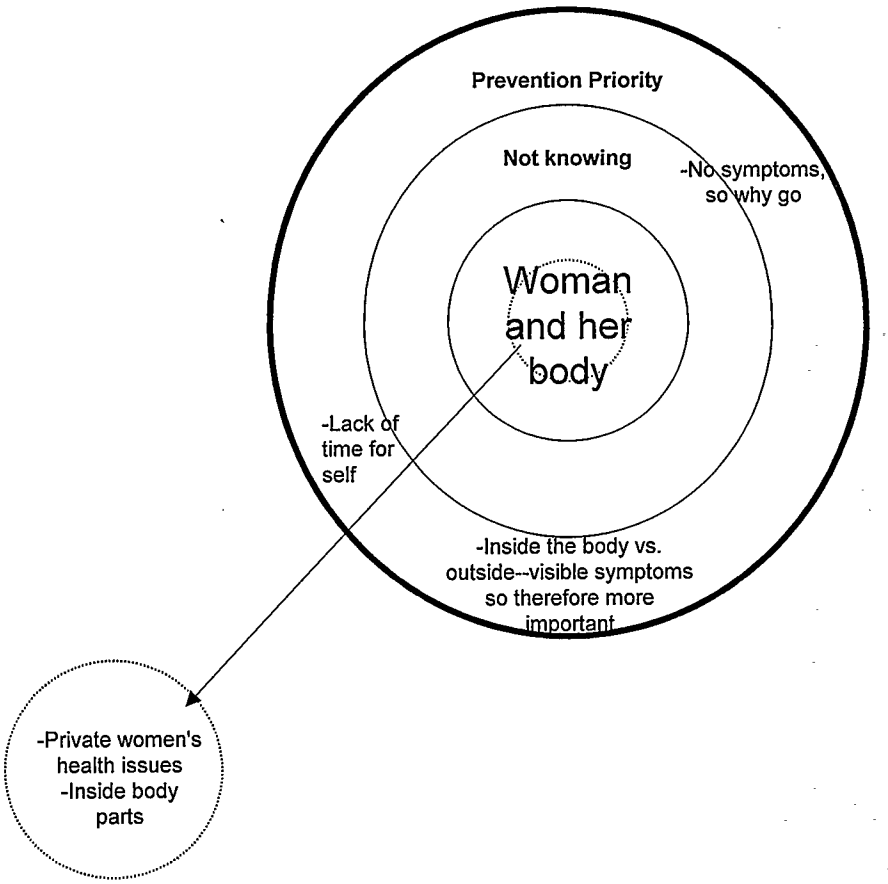
"Migration is a tremendous transformative experience for people. They engage themselves in a struggle to construct a new identity" (Talbani & Hasanali, 2000, p. 616). It is complex and full of change requiring adjustment in areas such as social conditions, culture and political issues (Boneva & Hanson Frieze, 2001; Luquis, 1995). Individuals must relearn roles and relationships affecting themselves as a person (Mettler, 1998).

Acculturation is a process whereby individuals or groups learn to adopt some of the behaviours, values, standards and practices of the host culture (Leininger & McFarland, 2002). Social identity theory maintains that acceptance by the majority is essential for minority individuals as described by Tajfel (1985) as cited by Kosic (2002). Krishnan and Berry (1992) found in their study of first and second generation South Asian immigrants to United States that those individuals born in India have a much greater desire to integrate into the host society than those who are second generation citizens of the host country.

Similarly, the Sikh women I interviewed had a strong yearning to belong to Canadian society, particularly to participate in health screening. Abouguendia and Noels, (2001) found that despite this strong desire, many challenges continue to prevent Canadian South Asian immigrants from participating more fully in the host society. Exploring the challenges experienced by Sikh women in moving into the outside world (mainstream society), assisted me to understand more fully the obstacles to cervical cancer screening for Sikh women in a large urban centre.

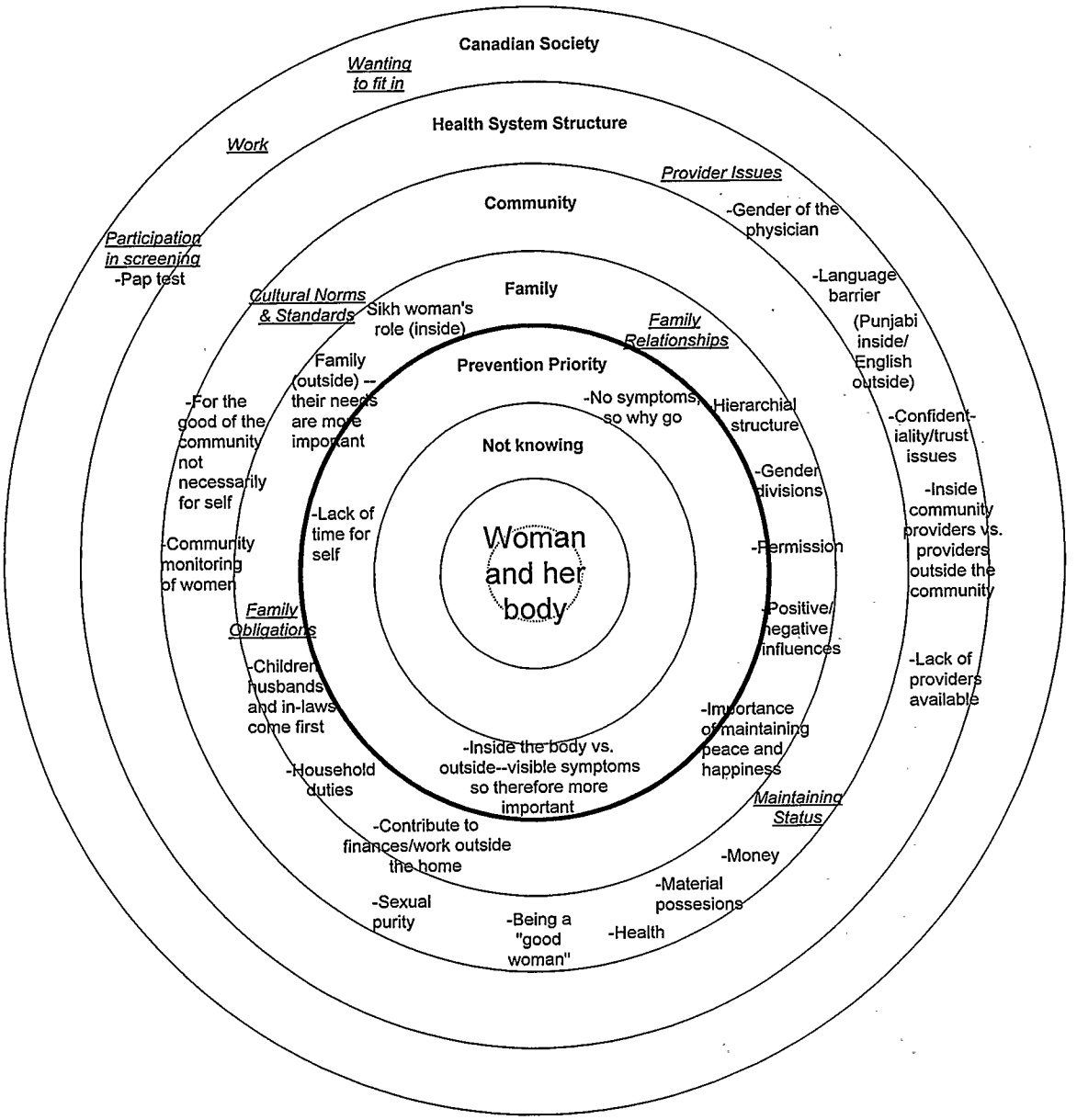
Findings have been summarized and are presented graphically in Figures 1 and 2. Figure 1 presents the woman and the barriers related to her as an individual—her body, lack of knowledge and the priority on prevention. In addition to these individual layers there exist the layers of family and community influence and health system barriers (Figure 2). The process is layered from the inside to the outside for the woman in negotiating the barriers to attending and receiving a Pap test. Obstacles must also be

Figure 1. Individual influences on cervical cancer screening



negotiated by health care professionals, from the outside to the inside, in reaching Sikh women with information and screening services. The layers of circles and issues within each layer are highly interconnected, therefore each circle must be examined within the context of components of the other circles in the figures. It is also important to note that the concept of inside/outside can be considered as a continuum with individuals

Figure 2. Dilemmas for Sikh women in cervical cancer screening.



participating in various activities at different levels of inside or outside their community.

Individual Circle

The graphic presentation begins with a woman in the center circle; this includes the physical, social, emotional and spiritual components of her *as a person*. The cervix is part of the inside of the body, distinctly different from those body parts that can be seen. Being an inner part of the body, the cervix, is less important than outside, more visible body parts. This circle also speaks to the very private nature of women's health issues, particularly those with sexual health connotations. Sikh women are strongly encouraged to keep these to themselves, within their own bodies. Gadow (1980) suggests in her study of the "woman's body," that women are looking for meaning of their body and its relationship to self and the outside world.

Knowledge Circle

The next circle represents women's lack of knowledge of the Pap test. Sikh women in general are neither aware of the Pap test nor why it should be done. For Sikh women inside their own community, there is limited knowledge; knowledge of screening and the purpose of the Pap test exists in the outside, external world. Studies of South Asian women also found knowledge to be a barrier to screening (Gupta, Kumar, & Stewart, 2002; Kernohan, 1996; Naish, Brown, & Denton, 1994). The Sikh community is not unlike women of other ethnocultural communities: African American (Harlan et al., 1991); Hispanic (Harlan et al., 1991); Korean (Lee, 2000); and rural Australian (Well

Women's Community Health Project, 1991).

Two consistent variables related to screening were identified in the current study—age and length of stay in Canada. In Alberta, both older women and new immigrants were less familiar with Pap screening. This echoes findings in earlier research that report lower Pap rates for older women (Maxwell, et al., 2001; Snider et al., 1996; White, et al., 1993) and new immigrants (Goel, 1994; Mandelblatt et al., 1999; Pham & McPhee, 1992).

Knowledge, itself is not sufficient for behaviour change (Prochaska, 1992; Rosenstock, Strecher, & Becker, 1988). Other issues need to be addressed to increase Sikh women's participation in cervical cancer screening.

Prevention Circle

A lack of focus on health promotion in the Sikh community poses another challenge for cervical cancer screening. When Sikh women become aware of the need for Pap tests, actual participation is minimal if no symptoms are present. If there are no visible, outside symptoms it is hard to justify a priority to attend for screening.

Several of the participants were asked about the beliefs of destiny or fate affecting the health of an individual in the Sikh culture and how this may influence health behaviours. It was assumed that if a Sikh woman felt she had no control over whether she would get cancer or not, she may not attend screening as this would be her pre-determined destiny. Participants did not seem to think that this was a significant influence in their particular Sikh community.

India's health care system differs significantly from the Canadian system impacting health decisions and screening behaviours of Sikh women. India has a population of over 1 billion (Census India, 2002); large segments of the population live in rural areas of India (where many of Calgary's immigrants originate) and India's rates of poverty are a major social issue (The World Bank, 2001). India's health system is made up of both publicly and privately funded services. Less than 1% of India's GDP is spent on public health care. Private health care spending is among the highest in the world at more than 80% of the total health care spending in the country. Most of the private spending "is out-of-pocket at the point of service" (The World Bank, 2001, p. 3) jeopardizing greatly the financial status of individuals and families. Only 10% of India's population has some form of health insurance, which is generally inadequate. The focus of health care in India is curative as opposed to western countries where there is a greater emphasis on disease prevention and health promotion.

Lack of priority on prevention was found to a barrier to cervical cancer screening in the South Asian community (Bottorff et al., 2001; Kernohan, 1996). Choudhry (1998) found that South Asian immigrant women do not practice health promotion behaviours as those women who originated in North America. Health was incorporated into everyday life, as part of their culture. Choudhry et al. (1998) also conducted a study of South Asian women's breast health practices. Women were unlikely to participate in a new, unknown health activity if symptoms were not present. As well, Bottorff et al. (1998) investigated breast health practices in the South Asian community in Vancouver, British

Columbia. They found that breast cancer screening was foreign to these women. There was no need to see a doctor if there were no symptoms present; in fact, some felt it was inappropriate to go to the doctor for "no reason."

Time is also a factor for these women especially for preventative health practices with no symptoms. Responsibilities for the family, community are significant. Coupled with outside work and continued full responsibility for children, extended family members and household chores, time for a Sikh woman herself is limited. Lynam et al. (2000) in a perinatal health study conducted with Indo-Canadian women in Vancouver, British Columbia comment on the heavy workload for some women coupled with the traditional responsibilities in the family and home. These women were seen to be high risk for problems during pregnancy and postnatally. Dyck (1993) also speaks to the lack of time available to women in the Indo-Canadian community.

Family Circle

Added to the circles of knowledge and prevention are further layers of challenges for women in obtaining screening. Evidence of cultural values and expectations is significant in the family with considerable impact on the behaviour of women in the Sikh community and ultimately on cervical cancer screening.

"Health is not an individual matter for South Asian women. Their health practices are influenced greatly by family and community responsibilities" (Bottorff et al., 1998, p. 2083). The context of the family is important in assessing a woman's individual health (Meadows, Thurston, & Melton, 2001). Choudhry et al. (1998) also

found health promotion behaviours to be greatly influenced by cultural standards and the family.

A better understanding of family dynamics in the Sikh community was gained by exploring related demographic information. Traditional Sikh family structures such as arranged marriages and extended family living arrangements continue to be prevalent within the Sikh community but do appear to be changing. This was particularly true when only a small number of women were found to be living with extended family. There are two possible explanations—the trend of extended families living together may be decreasing in Canada or our sample was not representative of the community.

Ralston (1997; 1998) in her study of South Asian women in Canada, Australia and New Zealand found that more than two thirds of participants had an arranged or semi-arranged marriage. Many women also immigrated as part of a marriage contract much the same as occurred in this current study.

Choudhry (2001) states extended family living arrangements are a traditional custom in the South Asian community. The new wife will live with her husband and his extended family. Joint families are generally the norm for cultural and economic reasons.

In Sikh community society, permission was often needed for women to attend a medical appointment. Similar examples of patriarchal society were found in the literature. Goerge and Ramkinssoon (1998) in their qualitative study of 47 women found that South Asian women tended to live in a more traditional, patriarchal society. Ralston (1998) found that the potential domination by men in the family and community greatly

influenced South Asian women. Traditional South Asian culture views women as a possession to be managed by men—first by their fathers and then, through an arranged marriage, by their husbands (Bhopal, 1997). In studies of South Asian women, patriarchal culture was shown to be an important influence on breast health practices and other health promotion behaviours (Choudhry, 1998; Choudhry et al., 1998). Patriarchal practice also brings a measure of security to women within families and the community particularly for elderly women (Choudhry, 2001). Ahmad (2001) in her study of British, South Asian, Muslim women found that the value of women was changing as indicated by the support of daughters obtaining post-secondary education.

Women in this study respected the opinions of elders in their families and in the Sikh community. Sometimes they would not be in agreement, however continued to abide by their guidelines to avoid conflict within their families and the community.

Traditionally the elderly in India have been respected and hold an influential status in both the family and general society (Desai, 1999). Respect for elders in the family and community was also noted by Bottorff et al. (1998) and Choudhry (2001) in their separate studies of Canadian South Asian women. Elderly women provide younger women with advice on health issues. This is particularly true during pregnancy and postnatally where pregnant women and new mothers were discouraged from asking questions of health care professionals (Lynam et al., 2000).

The relationship between the mother-in-law and daughter-in-law is a very important relationship in all families, particularly those living in an extended family

situation. To avoid conflict within the family, this relationship is protected, sometimes at a great cost to the daughter-in-law. Once a relationship deteriorates it can be difficult to repair with potential negative consequences for the daughter-in-law. It is important to note that in this study the characteristics of relationships between mothers-in-law and daughters-in-law varied a great deal from one family to another.

Several examples of the hierarchical structure in the household are evident in the literature. Dyck (1993) in her exploratory study of 15 Sikh women found that the importance of in-laws was common to all participants. The lowest rung of the hierarchical ladder was occupied by daughters-in-law with the mother-in-law having control over the household (Bhopal, 1997; Choudhry, 2001). Competition for the son/husband and other issues has been found to cause problems between the mother-in-law and the daughter-in-law (Desai, 1999).

Roles in the family were gendered. Women were responsible for the children, other household members including husbands and in-laws and other household duties. In addition many worked outside the home. The literature outlines similar roles for women (Bhagat, Biring, Pandher, Quong, & Triolet, 1997; Bottorff et al., 1998; Desai, 1999; Dyck, 1993; Lynam et al., 2000; Ralston, 1997). Husbands look after the outside work and family finances (Dyck, 1993). Men, particularly husbands are to be cared for by the women (Bottorff et al., 1998; Ralston, 1997). Many of the women also work outside the home (Goerge & Ramkisson, 1998; Prashad, 1999) often in low paid, physically demanding occupations (Dyck, 1993; Lynam et al., 2000). Desai (1999) and

Lynam et al. (2000) state South Asian women find little time for themselves, impacting their health negatively. The philosophy of women in the South Asian community is putting others first (Bottorff et al., 1998); they are committed to their families before looking after themselves. Looking after others, coupled with the patriarchal society, causes women to focus on others and not their own health—maintenance or prevention (Choudhry, 1998).

Evidence in this study clearly outlines the impact of family dynamics and influences in the Sikh community and its affect on cervical cancer screening behaviours of women. The challenges imposed by the inside family seem not worth the effort it takes to reach the outside goal, especially when it is "only" for a check-up.

Community Circle

In addition to the family's influence there is also a larger community impact on health practices of Sikh women. Women live inside their own communities often interacting only with family members or other members of the Sikh community. Opportunities to interact with others outside, in Canadian society, can be limited. Sikh community members often monitor activities and actions of others in their community, particularly women. A number of issues were identified in the study related to maintaining honour and status of both the individual and family within the Sikh community, ensuring that life is normal, at least on the outside. These issues influence the health practices of Sikh women, affecting their ability to move from inside their own community to the outside to take part in health screening activities.

Women in the Sikh community have very limited opportunities for dialogue about female reproductive health, particularly those issues linked to sexuality. Women are strongly discouraged to talk about these types issues, including cervical cancer screening as consequences of dishonour and shame may arise. This lack of discussion has resulted in large gaps in knowledge and an increase in misinformation. Dissemination of any known information is minimal resulting in decreased participation of Sikh women in screening.

Other studies also support the privacy of this type of issue and modesty of women in the South Asian culture. Bottorff et al. (1998) found modesty and maintaining family honour were critical findings in relation to breast health practices. Children were taught these things from a young age. Gerrish (2001) states that sexual issues are very difficult to discuss within the South Asian community, leading to large communication gaps in this area. Discussion of sexual health in this community, "potentially compromising the chastity or honour of women" (Baraister, 1999, p. 145) was also noted in a previous study. Dwyer (2000) discovered that young South Asian, Muslim women in the United Kingdom were expected to maintain the family honour by adhering to cultural standards, particularly sexual standards. The entire community scrutinized adherence to these standards.

Results of the current study reveal the importance for women to maintain a "sense of normalcy" within the family and the larger Sikh community. Even if problems such as illness occur in the family, on the outside one must give the impression of everything

being okay. Bottorff et al. (1998) found that coping with everyday life activities was essential within the family and the larger South Asian community. Ensuring a usual routine portrays that all is well in the family. The appearance of a strong, healthy family was a priority to women in the South Asian community (Bottorff et al., 1998). Unhealthy individuals may affect the status of the family in the community, making it difficult to arrange marriages for their children. If women were to be seen attending the breast cancer screening clinic, community members may assume that the woman already has cancer. South Asian women also believed breast cancer was hereditary and ran in families (Johnson et al., 1999).

Sikh community members place a high priority on material possessions and money, striving for and maintaining a level of status within their community. Activities to support these ideals may influence health behaviours of Sikh women. Associated costs for screening (taking time off work, cost of drugs and other treatment if an abnormality was found) presented obstacles to getting a Pap test. Priorities of spending money on other items for the family or women themselves to portray well being or maintain status also impacted screening practices, particularly when no symptoms were present.

In a study (Choudhry, 2001) in Ontario, senior South Asian women felt that the present day society in their community was overly concerned about money and material possessions. Prashad (1999) in her description of South Asian culture discussed the need for women to work in order to compete for financial status with other families in the community and to impress family members back in India. Information on financial status

issues pertaining to the South Asian community was very limited in the literature. Cost, real or perceived, has long been shown to be a barrier to cervical cancer screening (Burak & Meyer, 1997; Coyne, Hohman, & Levinson, 1992; Jenkins, Le, McPhee, Stewart, & Ha, 1996; Mamon et al., 1990; Smith, Phillips, & Price, 2001).

The influence on South Asian women of maintaining status is well summed up with the following quote by Choudhry (1998):

> While they enjoy social support, they are closely watched by their own community to maintain their culture and gender roles. This may isolate them from the larger community and limit them from being exposed to, and from accessing, health promotion and prevention programs. (p. 270)

Bhopal (1997) also comments on women's behaviour in the community:

> South Asian women are constantly being judged on their performance as women...their behaviour is closely monitored. They must behave in accordance with cultural rules. (p. 491)

These issues keep Sikh women closely connected to their own community, decreasing the potential for participation in health promotion behaviours.

Health Care System Circle

The health care system in itself presents a number of challenges for Sikh women to obtain screening, especially for those that are not familiar with the system or those that do not speak English well. These include gender of the physician, language barriers, confidentiality and trust issues and lack of providers available. These components can

also be viewed in light of the concept of inside/outside. The ideal is for women to be seen by first language female providers moving towards the outside goal of participating in screening. Lack of culturally appropriate providers in this urban Sikh community is a very real problem. The ambivalence of confidentiality and trust of inside providers from their own community is also a concern.

Physicians are reportedly not informing Sikh women about the Pap test and its importance to stay healthy. Other health care professionals are also not reaching women in this urban Sikh community. This is not an uncommon barrier to cervical cancer screening. The literature reports the single biggest reason women do not obtain screening is that their doctors never recommended it (Coyne et al., 1992; Fox, Siu, & Stein, 1994; Glockner et al., 1992; Mamon et al., 1990; Well Women's Community Health Project, 1991). Choudhry et al. (1998) in her study of South Asian women's breast health practices found that a doctor's recommendation for mammography was a cue to action for screening. Fox (Fox, Breuer, & Wright, 1997; Fox et al., 1994; Fox & Stein, 1991) also found that a doctor's recommendation for mammography increased screening among all women, including those of various ethno-cultural backgrounds in the United States. Particularly influential was the doctor's enthusiasm in recommending mammography.

Women in the Sikh community perceived the gender of the physician to be a critical issue. Most women preferred a female health care provider to address women's health issues such as cervical cancer screening. Those who had more recently come from India were more accustomed to female providers such as midwives and community

health workers. Not only were women more comfortable, but men also preferred their women to be seen by a female physician. If a female provider was not available, cultural mores would then encourage the husband to attend the appointment with his wife.

Not only South Asian women prefer a female family physician; literature shows that women of various backgrounds, including Caucasian women, preferred that a Pap test be completed by a female provider (Ahmad, Gupta, Rawlins, & Stewart, 2002; Lurie, et al. 1993; Twinn & Cheng, 2000). Chugh et al. (1994) and Bottorff et al. (2001) found South Asians both in Vancouver and Calgary believed that only women should examine female patients.

Cervical cancer screening is an embarrassing topic for Sikh women to discuss. Many women found it difficult to ask a physician for a Pap test, whether the doctor was male or female. Similar findings were confirmed by Bottorff et al. (2001). Asking a doctor to do a Pap test was beyond a South Asian woman's capability.

Difficulty with the English language makes seeing a physician outside the Sikh community more difficult. Most women preferred a physician who spoke the Punjabi language and perhaps also had a good understanding of the culture of their community.

Chugh et al. (1994) in their research found that over 70% of South Asian community members preferred to see a health care professional who spoke the same language as they did. Freeman, et al. (2002) during a large patient satisfaction study in Britain found that many patients consulted physicians in a language other than English They concluded that it was advantageous for individuals to see a first language physician.

It increased the patient's understanding and general ability to cope. Many of the participants were of South Asian descent. The evaluation of the South Asian Pap Test Clinic in Vancouver showed that practitioners with a "common language and cultural knowledge" (Bottorff et al., 2001, p. 34) were most desired by women who attended the clinic.

Even with the difficulties of language, women were not necessarily sure it would be best to see a physician from inside the Sikh community. Issues of trust, confidentiality and standard of care are cited as barriers to seeing first language, community physicians. They were also concerned that Punjabi physicians from the Sikh community did not focus on check-ups and did not have time for wellness care.

Women interviewed in a study of Alberta rural mid-life women (Meadows, Thurston, & Berenson, 2001) made comparable comments that physicians were busy and overworked. These women showed little hope that due attention would be given to non-pressing health issues such as screening. In Twinn and Cheng's study (2000) of Chinese women, they reported that practical and communication skills of the provider affected the women's experience in receiving a Pap test therefore influencing their confidence in the physician.

Punjabi speaking Indian doctors are themselves not comfortable talking to women from their own community about Pap tests. In honouring their respect for women with an embarrassing topic the secret of cervical cancer screening remains hidden within the community and women are not being screened. Bottorff et al. (2001) also found that

physicians often avoided talking about the Pap test out of respect, because it was a difficult and embarrassing issue for the women.

Access to knowledge and the subsequent transfer of that knowledge is certainly not occurring among health care professionals servicing this large urban Sikh community. This is very frustrating for women. During the study we asked them about the Pap test, told them it was for cancer screening and that it should be done annually. Sikh women's frustration with providers in transferring this important knowledge is clearly evident. "How are we supposed to know about it?" V.B. Int010, Text Unit 129.

How, then, do Sikh women find out about Pap tests? This is difficult when suitable providers are not readily available, especially in Alberta's current climate of a shortage of family physicians.

Fitting Into Canadian Society

The dilemma for Sikh women is one of attempting to fit into Canadian society. There is a genuine desire to become part of the outside society, to participate in cervical cancer screening. The circles of obstacles that women must negotiate to attend for screening (such as gender roles, family and community influences and provider issues) have been outlined. What does this *really* mean for women in the process of prevention? Sikh women are not free to do and discuss what they need for screening and may not have knowledge about the Pap test. Their culture suggests they need female practitioners, but few are available. Therefore, there is an urgent need to rethink what services, and by whom these are offered, to Sikh women. As there are only several

Punjabi speaking physicians available and only one of them is a female, a possible solution is the use of trained nurses for screening in well women's clinics. Indeed, in the study many women expressed eagerness to know more about cervical screening being sponges for knowledge and action. The tendency of information to be spread by word of mouth increases potential for information to be disseminated and screening to follow.

Various methods were recommended by participants to reach women in the Sikh community with important information. These included media, small group education, one-to-one education, first language resource materials, and provider strategies. Most of the women thought if they knew about screening they would certainly attend. It is unlikely that knowledge itself will be sufficient to negotiate the many obstacles that exist for Sikh women. The obstacles are numerous and require a consistent effort on the part of women themselves and the health care system to increase screening participation in the Sikh community. Nevertheless, women were very interested in cervical cancer screening and enthusiastic to learn more. There is a hunger for knowledge among women in this community and a need to have a safe, comfortable environment to discuss these types of issues. A supportive environment is critical to move Sikh women from the inside to the outside.

Women recommended the use of ethno-specific media channels to reach women, particularly TV, which is very popular in the Sikh community. TV talk show formats have been used successfully both here in Canada and in India. Health care professionals and key community women presented information and important health messages.

Recognizable community members were very popular with women in rural communities in India. The development of personal skills in the form of knowledge and awareness of the Pat test is an important first step in moving women to the outside, to participate in screening.

Several media initiatives to promote breast and cervical cancer screening to underserved populations are outlined in the literature (Jenkins et al., 1999; Shelley, Irwig, Simpson, & Macaskill, 1991). These have produced few positive results. Media strategies are also difficult to evaluate as they are often used in multi-strategy projects (Oelke, 2002).

A specific type of media intervention, "participatory communication" in conjunction with volunteer lay health workers was used in a Texas border town with Spanish speaking Mexican American women (Ramirez et al., 1999). Participatory communication is a media strategy based on behavioural journalism and the principle of diffusion using peer role models from the community. Partnerships were developed with local media with community members presenting information on cervical cancer screening by sharing their own personal stories. These were aired as interviews on talk shows, newscasts or published in newspapers. Coupled with the education and resources provided by volunteers in the community there was a significant increase in participation in Pap testing. This model was used in other projects with Mexican American women in Texas with mixed success for both mammography and Pap testing (McAlister et al., 1995; Ramirez et al., 1995; Suarez et al., 1997).

"Education camps" have previously worked well in this community addressing a number of health issues such as mammography and diabetes. Women are eager to learn more information about their health. They are also concerned about missing out; therefore presentations at the *gurdawara* are especially successful as curiosity and wanting to be involved draws women in. Increasing women's personal skill in the area of knowledge is important. "Education camps" can also provide a supportive environment for Sikh women to learn about cervical cancer screening in their community. These ways can assist women to begin the journey to move from the inside to the outside.

Word of mouth and the existing informal network of women were most apparent in the Sikh community. Networks of friends and family were discussed numerous times by participants throughout the study. Building the capacity of women in the community to reach others could be an important way of transferring Sikh women from the inside to the outside, to participate in screening. The use of peers can also assist in creating a supportive environment for discussion, transfer of knowledge and the actual process of screening.

The use of peers, either volunteer or paid, can be an effective way of reaching women with important health messages such as cervical cancer screening. Lay health worker initiatives have been successfully used in a number of different communities to increase cervical cancer screening (Dignan et al., 1993; Dignan et al., 1995; Dignan et al., 1996; Dignan et al., 1998; Jackson et al., 2000; Messer, Steckler, & Dignan, 1999; Ramirez et al., 1999). They have also been commonly used to promote breast cancer

screening (Burhansstipanov, Dignan, Wound, Tenney, & Vigil, 2000; Burhansstipanov et al., 1998; Calle, Miracle-McMahill, Moss, & Heath, 1994; Derose et al., 2000; Duan, Fox, Derose, & Carson, 2000; Erwin, Spatz, & Turturro, 1992; Skinner, Arfken, & Waterman, 2000; Skinner et al., 1998; Slater et al., 1998). Combined breast and cervical screening projects with lay health workers are also documented (Bird et al., 1998; Curry, Moen, Morris, & Scheivelhud, 1994; Goldsmith & Sisneros, 1996; Gotay et al., 2000; Hiatt et al., 2001; Kelly et al., 1996; McAlister et al., 1995; McCooey, Mitchell, Parker, & Simpson, 1999; McPhee et al., 1996; Navarro et al., 1995; Ramirez et al., 1995; Suarez, Nichols, & Brady, 1993; Suarez, Nichols, Pulley, Brady, & McAlister, 1993; Sung et al., 1992). In addition, numerous other health promotion issues have been addressed by peer health workers over the years and are documented in a literature review (Oelke, 2001).

In the South Asian community lay health workers have been utilized for a number of different initiatives. In Britain (McAvoy & Raza, 1991) lay health educators from the community were used to promote cervical cancer screening. The personal visit from the health educator along with a video or written materials was most effective in reaching women. Link workers were employed in the inner city of London to reach multi-ethnic women with cervical and breast cancer screening information (Kernohan, 1996) and showed a significant increase in Pap testing and mammography screening, especially in the South Asian community. Community mothers were used successfully in reaching South Asian women regarding parenting concerns (Jackson, 1992). Other studies

conducted in Canadian South Asian communities have noted that women learn from other women in the community (Bottorff et al., 1998; Choudhry et al., 1998; Lynam et al., 2000). Theirs is an oral culture where storytelling is important. This large informal network of women has to date been largely untapped (Lynam et al., 2000).

"Word of mouth is a very powerful tool " M.K. Int008, Text Unit 188. If information is given to the right people knowledge of the Pap test can be transferred to Sikh women, hopefully increasing screening activity and moving them from the inside to the outside by participating in cervical cancer screening.

First language materials specific to Pap tests were highly recommended by women in the study. These materials could be distributed to various community locations, especially doctors' offices. There were differing opinions on whether a pamphlet or other written resource materials would be successful in reaching women or not. It was apparent that although it is important to have these written materials, these alone would not likely make a big difference in women's screening practices. Choudhry et al. (1998) in her study on breast health practices found that women also wanted educational materials in their first language.

Provider issues and the associated challenges have previously been discussed in this chapter. As suggested by participants, working with family physicians is one important strategy to reach Sikh women as physicians have a significant influence on South Asian women's health practices (Bottorff et al., 1998; Gupta et al., 2002).

Women were also asked about the potential of nurse provided Pap screening for

the Sikh community to increase their access to culturally appropriate, inside providers. This suggestion was positively received by participants and seen as a way to resolve some of the barriers to screening for Sikh women. Re-orienting current health care services is important in being able to address issues of access for Sikh women.

The South Asian Pap Test Clinic (Bottorff et al., 2001) was established several years ago in Vancouver, British Columbia. A trained nurse working in partnership with a physician provides Pap tests in bimonthly clinics. Both the nurse and the physician are first language health care professionals. In a qualitative evaluation, women were very satisfied with the service; they appreciated the time spent giving thorough explanations of the procedure. They felt comfortable and the clinic provided a safe place to discuss health issues.

Several other successful examples of nurse-delivered cervical cancer screening services exist in the literature. An evaluation of a project (Well Women's Community Health Project, 1991) in rural Australia showed a large number of women being screened following promotion and tests offered by trained nurses. Many of the women who participated were underscreened and represented various ethno-cultural language groups. Again women were very pleased with the service. In another intervention (Brown & Byles, 1996), Australian nurses collaborated with physicians to reach high risk women. A significant increase in cervical cancer screening was noted, with improvement in access and coverage of screening in the community. In Hong Kong women who participated in a number of focus groups stated they would choose a Pap test by a trained

nurse over a family doctor (Twinn & Cheng, 2000). Similar projects were carried out in the United States (Brown, 1996; Mandelblatt et al., 1993; Margolis, Lurie, McGovern, Tyrrell, & Slater, 1998) with low income women of various cultural groups. There was a significant increase in cervical cancer screening especially when same day appointments were offered.

Numerous layers of obstacles to cervical cancer screening exist for women in this urban Sikh community as illustrated in Figures 1 and 2. One woman clearly summarizes the situation, "It's just, there's so many hassles and problems that come with just going to visit the doctor that they rather not." D.M. GrInt001, Text Unit 468. It is the hope that the results of this study will assist health care providers to more fully understand the situation of these women and begin to address ways to assist them to move to the "outside" goal of regularly participating in cervical cancer screening and other health promotion activities.

Reflections on Method

Cross-cultural research can be very complex. Reflecting on the methodology utilized in this study provides important learnings for future research with the Sikh community and other ethnocultural groups.

Theoretical Framework

Empowerment education (Freire, 1994; Wallerstein & Berstein, 1994) provided the approach to working with underserved communities, being respectful and allowing them to formulate their own solutions. Prior to the initiation of this study, several key

women in the Sikh community had requested awareness interventions be undertaken on cervical cancer screening due to the lack of participation of Sikh women in this health activity. This request provided the foundation and impetus for this study. In addition to information collected on challenges to cervical cancer screening, women also provided recommendations on how to reach women with important information. Information on cervical cancer screening and access to services was provided at the end of each of the interviews and focus groups, empowering women in their ability to attend for screening. A serendipitous effect of recruitment of women for the study was an increase in awareness of cervical cancer screening among women in the community. The strong desire of women wanting their friends and family members to know about the issue was aligned with my objective and assisted in the recruitment of women. The result, a form of empowerment education referred to by Wallerstein and Berstein (1994).

The theory of transcultural nursing (Leininger, 1991) provided a basis for the data collected. Women were asked questions about culture, environment, and social structure to gain a deeper understanding of the barriers to cervical cancer screening. The Sunrise Model (Leininger 1991) facilitated understanding the complexity of these barriers during data collection and analysis.

Inherent in the solutions suggested by participants to reach women in their community with screening information are the various components found in the health promotion framework. In addition, the study created a supportive environment for Sikh women to share information about cervical cancer screening. Information to develop

women's personal skills (knowledge and awareness) was also provided by the researcher encouraging women to seek screening services.

Recruitment of Participants

Participants for the study were recruited in a variety of ways. The most effective way of recruiting women for the study was by word of mouth through key community members. This strategy legitimized the study and assisted in gathering participants through existing networks of community leaders. Similar recommendations are found in the literature in recruiting immigrant women in a research study. Neufeld, Harrison, Hughes, Spitzer, and Stewart (2001) state that personal communication is the best way to reach women.

A concern when conducting research with an ethnocultural community is access to participants. Research that includes immigrant women is essential if we want to hear their stories and understand better their health challenges (Neufeld et al., 2001). Issues in reaching these women are the same as those that identify them as being at risk and having difficulty accessing health services. Because of my previous work in this community, engagement with key individuals was already established. Lincoln and Guba (1985) suggest that prolonged time with a population builds trust and understanding of context that facilitates access.

Mixed information on the advantages and disadvantages of an outsider interviewing women in a cultural community exists in the literature. Confidentiality is seen as one of the biggest concerns with an "inside" interviewer, although these same

women, if respected by the community, have an established trust and network that the outside interviewer does not (Dyck, 1993; Neufeld et al., 2001). It is also important to note that a person from the community may not guarantee homogeneity (Dyck, Lynam, & Anderson, 1995). In other words an individual can be a language broker but not necessarily a cultural broker. This may be of particular concern in the South Asian context due to its diversity of groups within the community. Ralston (1998) found that the South Asian women in her studies chose to speak to someone from outside of the community for reasons of confidentiality, trust, and honesty.

Numerous questions regarding cross-cultural research have arisen in the literature. Ralston (2001), a Caucasian feminist researcher, in her work with South Asian women summarizes some of these questions. She discusses the ethics of doing research with minority populations; who owns the project and the research results, the motivation of doing this type of research, and whether someone from outside the community can understand women's experiences. She cautions individuals about bias and ethnocentrism. She defines cross-cultural research as exploring:

> ...culturally specific factors with a view to building bridges and creating common space between women of color and white women and to facilitating positive social change in our everyday world. (p. 214)

Awareness of the power relationship between the researcher and participant is important particularly when it is associated with difference in race (Bhopal, 1995; Dyck et al., 1995). This may have a significant influence on the quality of the interview and

the information gathered. Bhopal (1995) suggests that the South Asian community is very private and reluctant to share information about themselves, their families and their culture. A person from outside of the community may be perceived as a threat. Women interviewing women may not be enough to construct shared understanding and meaning because of personal assumptions, values, culture and past experiences that may impact the research process. It is impossible to be completely objective; but it is important to have a balance between rapport and trust as well as maintaining objectivity by keeping a distance to have insight into the experiences of the women. Naturalistic inquiry (Lincoln & Guba, 1985) recommends that researchers examine their own values and potential biases by bracketing preconceived beliefs and judgments of the phenomena under study.

Methods

Leininger (Leininger & McFarland, 2002) strongly recommends the use of qualitative methods to study care and culture in context. Therefore naturalistic inquiry was used as a basis for data collection and analysis for the study. These qualitative methods were especially helpful in understanding the complex obstacles to cervical cancer screening in Sikh women. Leininger (1991) encourages the qualitative researcher to take an in-depth look at actual and/or potential influencers on health, including the researcher's own bias as well as those of the health care system. This information was used in reflecting on the data throughout the study.

Focus groups were used as one method to collect data from Sikh women during the study. Due to the enthusiasm for women to be involved in the process, two of the

three focus groups were quite large with 16-18 participants. At times it was difficult to facilitate group process due to the size of the groups. In future research in this community, it would be important to reconsider this method of data collection in this population. Focus groups in a controlled setting rather than at a public location would be more appropriate. Large groups also reduced the depth of information gathered. The depth of information during interviews was much greater than in the focus groups. Sikh women may feel uncomfortable sharing in-depth, private information in a group setting. The literature indeed supports such an observation; the discussion of private issues is very difficult for Sikh women (Baraister, 1999, Bottorff, et al., 1998, Gerrish, 2001) as discussed elsewhere in this report.

Summary

Discussions of findings from the study presented here provide a wide range of perspectives on cervical cancer screening for Sikh women. Potential solutions suggested by women are also discussed. The obstacles noted here are similar to those outlined in the literature with other communities. Both of these components provide much needed information for cervical cancer screening program planning both for the Sikh community and others. Reflections on methodology provide helpful data for future research with the Sikh community or similar research in other ethnocultural communities. Limitations of this study as well as considerations for future research are reviewed in the conclusion.

CHAPTER EIGHT—CONCLUSION

The research was conducted with respect for the community and facilitated the process of exploring issues around cervical cancer screening in an urban Sikh community. Information on cervical cancer screening was also provided to women in interviews and focus groups. Data collected from women will be returned to the community in a confidential, understandable manner as it ultimately belongs to these women.

Several limitations of the study should be considered. It is important to bear in mind that ethnocultural communities are not homogenous. There is often as much variation within groups as there is between groups. Efforts were employed to recruit women for maximum variation in age, length of stay in Canada and searching for multiple realities. Despite these efforts caution is recommended in generalizing results to all women in the Sikh community. Findings do provide a beginning point in understanding cervical cancer screening in these women. These discussions may provide important insight for women of other immigrant groups as well.

Issues are often found in conducting research in another language. The same interpreter and facilitator were used for all interviews and focus groups to maintain consistency when data was collected. Third party individuals need to be neutral and interpret information completely and accurately (Kaufert & Putsch, 1997). This is not always the case and can be difficult to control when the researcher does not speak the language. To avoid inaccuracies that may have occurred during interpretation, all

Punjabi tapes were translated and transcribed in their entirety outlining all information stated by the participant, interpreter or facilitator and researcher. It is also important to note that language interpreters are not necessarily cultural interpreters. Issues of "class, power, disparate beliefs, lack of linguistic equivalence, or the disparate use of language" (Kaufert & Putsch, 1997 p. 72) are much more difficult to address.

Another limitation of the study was the unfortunate circumstance of losing some data from one of the focus groups. This was addressed by attempting to recreate the data with focus group facilitator, organizer and observer. An additional focus group was conducted to provide further data for analysis.

Overall the information presented in the findings has shown that there are many factors that impact cervical cancer screening in Sikh women. These various aspects indeed influence participation and access to screening services. These challenges need to be taken into account in cervical cancer screening program planning for these women.

The concept of inside/outside, referred to throughout the data collected, is interesting and requires further study to fully understand the phenomenon, its relationship to Sikh women and to cervical cancer screening. A phenomenological study would assist in providing an in-depth exploration and appreciation ideas and women's experiences.

Strategies to reach women were suggested by participants in the study. Intervention-based research to study the effectiveness of these approaches would assist in further understanding cervical cancer screening in the community as well as provide an opportunity to evaluate initiatives to promote screening.

Although this study was conducted to explore the perspectives of Sikh women on cervical cancer screening, throughout data collection and analysis processes one realizes it is about much more. Many of the challenges and influences provide a picture of the Sikh woman's response to many different aspects of health. In reality it is about women's health inclusive of cervical cancer screening.

Findings from this study will have important implications on cervical cancer screening programs as well as other screening initiatives and women's health promotion in this community.

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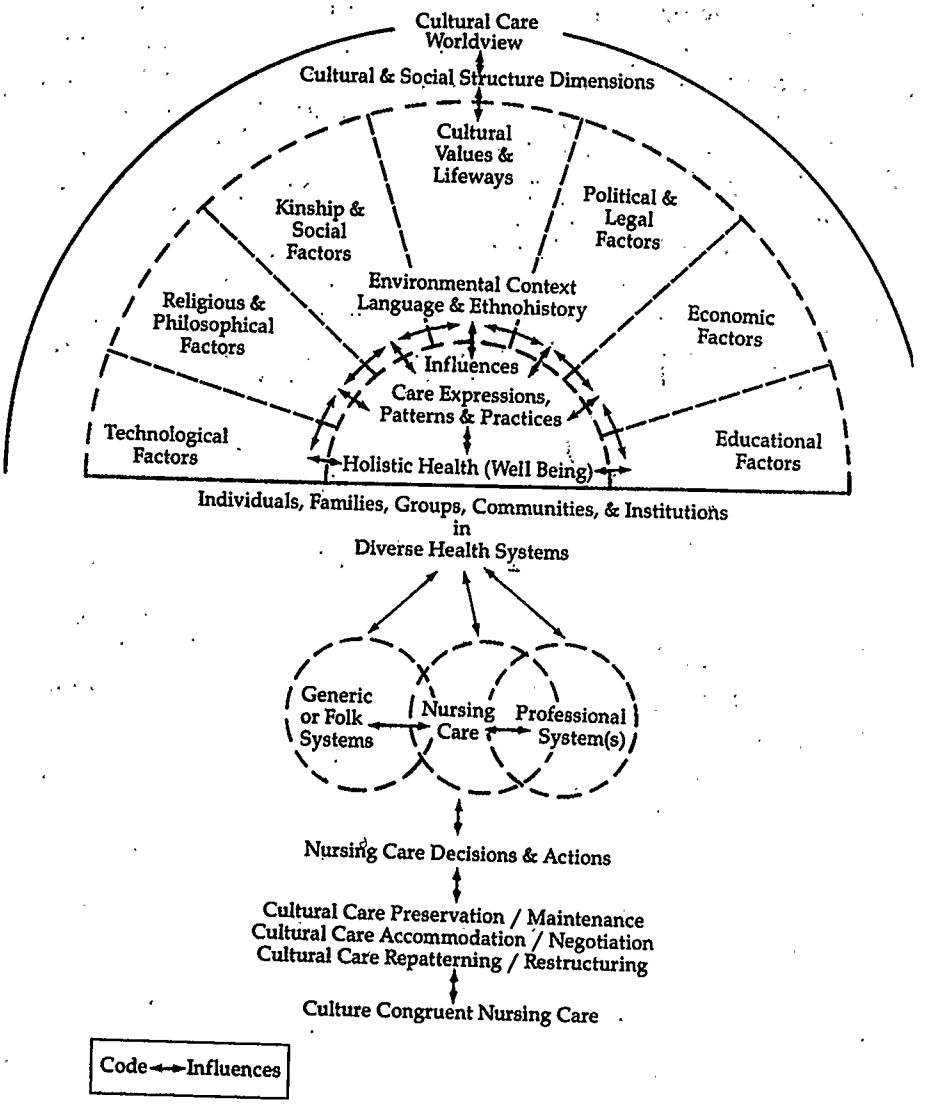
APPENDIX A—SUNRISE MODEL

Figure 1
Leininger's Sunrise Model to Depict Theory of Cultural Care Diversity and Universality



Note. From "The theory of culture care diversity and universality," by M. M. Leininger, 1991, In M. M. Leininger (Ed), *Culture Care Diversity & Universality: A Theory of Nursing*, p. 43, New York, NY: National League for Nursing Press.

APPENDIX B—ETHICAL APPROVAL

UNIVERSITY OF CALGARY

FACULTY OF MEDICINE

Office of Medical Bioethics
Heritage Medical Research Building/Rm 93
Telephone: (403) 220-7990
Fax: (403) 283-8524

2001-04-19

Dr. A. Vollman
Faculty of Nursing
PF 2241
University of Calgary
Calgary, Alberta.

Dear Dr. Vollman:

Re: An Exploration of Cervical Cancer Screening Among Women in an Urban Sikh Community
Student: Ms. N. Oelke Degree: MN

The above-noted thesis proposal has been submitted for Committee review and found to be ethically acceptable. Please note that this approval is subject to the following conditions:

(1) a copy of the informed consent form must have been given to each research subject, if required for this study;
(2) a Progress Report must be submitted by 2002-04-19, containing the following information:
    (i) the number of subjects recruited;
    (ii) a description of any protocol modification;
    (iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
    (iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
    (v) a copy of the current informed consent form;
    (vi) the expected date of termination of this project;
(3) a Final Report must be submitted at the termination of the project.

Please note that you have been named as a principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.

Yours sincerely,

Christopher J. Doig, MD, MSc, FRCPC
Chair, Conjoint Health Research Ethics Board

cc: Adult Research Committee
Dr. M. Reimer (information)
Ms. N. Oelke

APPENDIX C—RECRUITMENT POSTER

Sikh women participants needed

To take part in Nursing Research
"Cervical Cancer Screening (Pap Tests)"

Are you a woman between 18 and 69?
Are you a member of the Sikh community?

We would like to hear from you!

Volunteers will have a choice of doing an individual interview or taking part in a small discussion group.

An interpreter will be provided if needed.
All your information will be kept confidential.

To volunteer or for more information, please call:

Nelly Oelke RN – 274-4758
Dr. Ardene Vollman – 220-8053

***This research study is being conducted by the Faculty of Nursing, University of Calgary.**

ਸਿੱਖ ਔਰਤਾਂ ਦੇ ਯੋਗਦਾਨ ਦੀ ਜ਼ਰੂਰਤ ਹੈ

ਨਰਸਿੰਗ ਰੀਸਰਚ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੇ ਕੈਂਸਰ ਦੀ ਸਕਰੀਨਿੰਗ (ਪੈਪ ਟੈਸਟ)

ਕੀ ਤੁਸੀਂ 18 ਸਾਲ ਤੋਂ 69 ਸਾਲ ਦੀ ਉਮਰ ਦੇ ਵਿਚਕਾਰ ਦੀ ਔਰਤ ਹੋ?
ਕੀ ਤੁਸੀਂ ਸਿੱਖ ਕਮਿਊਨਿਟੀ ਦੇ ਮੈਂਬਰ ਹੋ?

ਅਸੀਂ ਤੁਹਾਡੇ ਤੋਂ ਸੁਣਨਾ ਚਾਹੁੰਦੇ ਹਾਂ!

ਵਲੰਟੀਅਰ ਆਪਣੀ ਇੱਛਾ ਅਨੁਸਾਰ ਚਾਹੁਣ ਤਾਂ ਇਕੱਲਿਆਂ ਦੀ ਜਾਂ ਛੋਟੇ ਗਰੁੱਪ ਵਿਚ ਵਿਚਾਰ ਵਟਾਂਦਰਾ ਕਰਨ ਲਈ ਭਾਗ ਲੈ ਸਕਦੇ ਹਨ।

ਜ਼ਰੂਰਤ ਅਨੁਸਾਰ ਦੋਭਾਸ਼ੀਏ ਦੀ ਸਹਾਇਤਾ ਵੀ ਦਿੱਤੀ ਜਾਵੇਗੀ।

ਆਪ ਨਾਲ ਜੋ ਵੀ ਗੱਲਬਾਤ ਹੋਵੇਗੀ ਉਹ ਗੁਪਤ ਹੀ ਰਹੇਗੀ।

ਵਲੰਟੀਅਰ ਕਰਨ ਲਈ ਜਾਂ ਹੋਰ ਜਾਣਕਾਰੀ ਵਾਸਤੇ ਕ੍ਰਿਪਾ ਕਰਕੇ ਹੇਠ ਦਿੱਤੇ ਨੰਬਰ ਤੇ ਫੋਨ ਕਰ ਸਕਦੇ ਹੋ

Nelly Oelke RN: 274-4758
Dr. Ardene Vollman: 220-8053

* ਇਹ ਰੀਸਰਚ ਫੈਕੁਲਟੀ ਆਫ ਨਰਸਿੰਗ ਕੈਲਗਰੀ ਯੂਨੀਵਰਸਿਟੀ ਦੁਆਰਾ ਹੋ ਰਹੀ ਹੈ।

APPENDIX D—CONSENT FORMS

UNIVERSITY OF CALGARY

FACULTY OF NURSING

Telephone: (403) 220-3053
Fax: (403) 284-4803
Email: arvollma@ucalgary.ca

INTERVIEW CONSENT FORM

Research Project Title: **An Exploration of Cervical Cancer Screening Among Women in an Urban Sikh Community**

Investigator(s): **Nelly D. Oelke, Masters of Nursing Student**

Supervisor: **Dr. Ardene Robinson Vollman, Faculty of Nursing**

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this information carefully and to understand any accompanying information.

1. Purpose of the research study and our participation

You are invited to take part in a research study. It will look at the views of cervical cancer screening (having a Pap test) of women in the Sikh community. We would like to learn what cervical cancer screening means to women and why they take part in screening or not. We also want to find out how resources and services could best be carried out in your community.

The findings of this research study will give important facts about cervical screening in your community. The information will be used to plan services that will help more women take part in cervical cancer screening over the next few years.

You have been asked to take part because you have shown you are willing to share your understanding and experience of cervical screening. Data will be collected by interviews. The interview will be about 1½ hours long. You may be asked for a second interview of about 45 minutes to allow the researcher to ask more questions if needed. You may decline to participate in the second interview if you like. You will only be asked for the time needed for each interview. Interviews will be done in a place that works well for both of us, such as your home. We will provide an interpreter if you like.

2. Your rights as participants

You will be asked if it is okay to tape-record the interview with the researcher (and interpreter). Notes will also be taken. You may ask at any time during the interview that the tape-recorder be turned off. You can say no to any of the questions and end your part in this research study at anytime. You also have the right to ask questions and ask for more information whenever you like.

Your name or any group or agency that you may be part of will not be used in the study. Only the researcher(s) will be able to get any information from the study. Privacy will be kept for women

interviewed. There are no known risks for women but if at any point in time unexpected situations happen, suitable referrals will be made with your consent.

Code names or numbers will be used on transcripts and field notes. You have the right to get and read a written transcript of any taped interview in which you took part. Field notes, audio tapes, and any information with your name on it such as consents will be stored and locked at the University of Calgary, Faculty of Nursing.

Ideas and quotes from interviews will be used for the final report, publications and presentations of the research information, but at no time will you be known by your name or in any other way. Anonymity and privacy will be assured as much as possible. You may have a copy of the final research report.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at anytime without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact:

Nelly D. Oelke
Masters of Nursing Student
Faculty of Nursing, University of Calgary
Phone: 274-4758

Dr. Ardene Robinson Vollman
Associate Professor
Faculty of Nursing, University of Calgary
Phone: 220-8053

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary at 220-3782.

Participant's Signature	**Date**
Researcher and/or Delegate's Signature	**Date**
Witness' Signature	**Date**

A copy of this consent form has been given to you to keep for your records and reference.

UNIVERSITY OF CALGARY

FACULTY OF NURSING

Telephone: (403) 220-7893
Fax: (403) 284-4803
Email: mareimer@ucalgary.ca

INTERVIEW CONSENT FORM

Research Project Title: An Exploration of Cervical Cancer Screening Among Women in an Urban Sikh Community

Investigator (s): Nelly D. Oelke, Masters of Nursing Student

Supervisor: Dr. Ardene Robinson Vollman, Faculty of Nursing

ਇਹ Consent ਫਾਰਮ, ਜਿਹੜਾ ਫਾਰਮ ਤੁਹਾਨੂੰ ਦਿੱਤਾ ਗਿਆ ਹੈ, ਉਸਦੀ ਕਾਪੀ ਹੈ ਅਤੇ ਇਹ Informed Consent ਦਾ ਇੱਕ ਹਿੱਸਾ ਹੈ। ਇਸ ਫਾਰਮ ਵਿਚ ਖੋਜ ਜਾਂ ਰੀਸਰਚ ਬਾਰੇ ਅਤੇ ਇਸ ਖੋਜ ਵਿਚ ਤੁਹਾਡੇ ਯੋਗਦਾਨ ਬਾਰੇ ਮੁਢਲੀ ਜਾਣਕਾਰੀ ਹੈ। ਜੋ ਜਾਣਕਾਰੀ ਇਸ ਵਿਚ ਹੈ ਜੇ ਤੁਸੀਂ ਉਸ ਬਾਰੇ ਵਿਸਥਾਰ ਨਾਲ ਜਾਨਣਾ ਚਾਹੁੰਦੇ ਹੋ ਜਾਂ ਜੋ ਜਾਣਕਾਰੀ ਇਸ ਫਾਰਮ ਵਿਚ ਨਹੀਂ ਹੈ, ਤੁਸੀਂ ਉਸ ਜਾਣਕਾਰੀ ਨੂੰ ਵੀ ਬਿਨਾਂ ਝਿਜਕ ਤੋਂ ਵਿਸਥਾਰ ਵਿਚ ਪੁੱਛ ਸਕਦੇ ਹੋ। ਕ੍ਰਿਪਾ ਕਰਕੇ, ਤੁਸੀਂ ਖੁੱਲ੍ਹਾ ਸਮਾਂ ਲੈ ਕੇ ਇਸ ਜਾਣਕਾਰੀ ਨੂੰ ਧਿਆਨ ਨਾਲ ਪੜ੍ਹ ਕੇ ਸਮਝਣ ਦੀ ਕੋਸ਼ਿਸ਼ ਕਰਨਾ।

1. ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਦਾ ਉਦੇਸ਼ ਅਤੇ ਸਾਡਾ ਯੋਗਦਾਨ:

ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਦੇ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਤੁਹਾਨੂੰ ਨਿੰਮਤਰਨ ਹੈ। ਇਹ ਵਿੱਦਿਆ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੇ ਕੈਂਸਰ ਦੀ ਸਕਰੀਨਿੰਗ ਬਾਰੇ (ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਬਾਰੇ), ਸਿੱਖ ਕਮਿਊਨਿਟੀ ਦੀਆਂ ਔਰਤਾਂ ਦੇ ਵਿਚਾਰਾਂ ਵੱਲ ਧਿਆਨ ਦੇਵੇਗੀ। ਅਸੀਂ ਜਾਨਣਾ ਚਾਹੁੰਦੇ ਹਾਂ ਕਿ ਔਰਤਾਂ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੇ ਕੈਂਸਰ ਬਾਰੇ ਕੀ ਜਾਣਦੀਆਂ ਹਨ ਅਤੇ ਉਹ ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਵਿਚ ਹਿੱਸਾ ਲੈਂਦੀਆਂ ਹਨ ਜਾਂ ਨਹੀਂ। ਅਸੀਂ ਇਹ ਵੀ ਜਾਨਣਾ ਚਾਹੁੰਦੇ ਹਾਂ ਕਿ ਕਿਸ ਤਰ੍ਹਾਂ ਇਹ ਸੇਵਾਵਾਂ ਤੁਹਾਡੀ ਕਮਿਊਨਿਟੀ ਵਿਚ ਪਹੁੰਚਾਈਆਂ ਜਾਣ ਤਾਂ ਕਿ ਵੱਧ ਤੋਂ ਵੱਧ ਔਰਤਾਂ ਇਹਨਾਂ ਸੇਵਾਵਾਂ ਨੂੰ ਪ੍ਰਾਪਤ ਕਰ ਸਕਣ।

ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਦੇ ਸਿੱਟੇ ਜਾਂ ਨਤੀਜੇ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੇ ਕੈਂਸਰ ਦੀ ਸਕਰੀਨਿੰਗ ਬਾਰੇ (ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਬਾਰੇ) ਤੁਹਾਡੀ ਕਮਿਊਨਿਟੀ ਵਿਚ ਮਹੱਤਵਪੂਰਨ ਜਾਣਕਾਰੀ ਦੇਣਗੇ। ਇਹ ਜਾਣਕਾਰੀ ਹੋਰ ਸੇਵਾਵਾਂ ਦੀਆਂ ਯੋਜਨਾਵਾਂ ਬਣਾਉਣ ਵਿਚ ਮੱਦਦ ਕਰੇਗੀ ਤਾਂ ਕਿ ਵੱਧ ਤੋਂ ਵੱਧ ਔਰਤਾਂ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੀ ਕੈਂਸਰ ਦੀ ਸਕਰੀਨਿੰਗ ਵਿਚ (ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਲਈ) ਆਉਣ ਵਾਲੇ ਸਾਲਾਂ ਵਿਚ ਹਿੱਸਾ ਲੈ ਸਕਣ।

ਤੁਹਾਨੂੰ ਇਸ ਵਿੱਦਿਆ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਕਿਹਾ ਗਿਆ ਹੈ ਕਿਉਂਕਿ ਤੁਸੀਂ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੇ ਕੈਂਸਰ ਦੀ ਸਕਰੀਨਿੰਗ ਬਾਰੇ (ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਬਾਰੇ) ਤੁਹਾਡੀ ਸਮਝ ਅਤੇ ਤਜਰਬੇ ਬਾਰੇ ਵਿਚਾਰ ਸਾਂਝੇ ਕਰਨ ਲਈ ਇੱਛਾ ਰੱਖਦੇ ਹੋ। ਜਾਣਕਾਰੀ ਜਾਂ Data ਆਹਮਣੇ ਸਾਹਮਣੇ ਭੇਂਟ ਵਾਰਤਾ ਨਾਲ, ਇੰਟਰਵਿਊ ਨਾਲ ਇਕੱਠਾ ਕੀਤਾ ਜਾਵੇਗਾ। ਮੁਲਾਕਾਤ ਜਾਂ ਭੇਟ ਵਾਰਤਾ ਤਕਰੀਬਨ ਡੇਢ ਘੰਟਾ ਲੰਬੀ ਹੋਵੇਗੀ। ਤੁਹਾਨੂੰ ਦੂਸਰੀ ਮੁਲਾਕਾਤ ਜਾਂ ਭੇਟ ਵਾਰਤਾ ਤਕਰੀਬਨ ਪੰਤਾਲੀ ਮਿੰਟ ਲੰਬੀ ਹੋਵੇਗੀ, ਲਈ ਵੀ ਪੁੱਛਿਆ ਜਾ ਸਕਦਾ ਹੈ ਤਾਂ ਕਿ ਰੀਸਰਚ ਕਰਨ ਵਾਲਾ ਨੋਟ ਪੈਣ ਤੋਂ ਹੋਰ ਪ੍ਰਸ਼ਨ ਪੁੱਛ ਸਕੇ। ਜੇ ਤੁਸੀਂ ਦੂਸਰੀ ਮੁਲਾਕਾਤ ਵਿਚ ਹਿੱਸਾ ਨਹੀਂ ਲੈਣਾ ਚਾਹੁੰਦੇ ਤਾਂ ਮਨ੍ਹਾਂ ਵੀ ਕਰ ਸਕਦੇ ਹੋ। ਮੁਲਾਕਾਤ ਲਈ ਜਿੰਨਾਂ ਵਕਤ ਜ਼ਰੂਰੀ ਹੈ ਉੱਨਾਂ ਹੀ ਵਕਤ ਲਿਆ ਜਾਵੇਗਾ। ਮੁਲਾਕਾਤ ਉਸ ਜਗ੍ਹਾ ਤੇ ਕੀਤੀ ਜਾਵੇਗੀ ਜਿਹੜੀ ਸਾਨੂੰ ਦੋਹਾਂ ਨੂੰ ਸੁਖਾਲੀ ਹੋਵੇ ਜਿਵੇਂ ਕਿ ਤੁਹਾਡੇ ਆਪਣੇ ਘਰ ਵਿਚ। ਜੇ ਤੁਸੀਂ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਅਸੀਂ ਦੋਭਾਸ਼ੀਏ/Interpreter ਦੀ ਸਹਾਇਤਾ ਵੀ ਲੈ ਸਕਦੇ ਹਾਂ।

2. ਤੁਹਾਡੇ ਹੱਕ, ਹਿੱਸਾ ਲੈਣ ਵਾਲਿਆਂ ਦੇ ਰੂਪ ਵਿਚ

ਰਿਸਰਚ ਕਰਨ ਵਾਲਿਆਂ ਨਾਲ (ਅਤੇ ਜੇ ਜਰੂਰਤ ਹੋਵੇ ਦੋਭਾਸ਼ੀਏ (Interpreter) ਮੁਲਾਕਾਤ ਟੇਪ ਤੇ ਰਿਕਾਰਡ ਕਰਨ ਬਾਰੇ ਤੁਹਾਡੀ ਸਹਿਮਤੀ ਬਾਰੇ ਪੁੱਛਿਆ ਜਾਵੇਗਾ। ਇਸਦੇ ਨਾਲ-ਨਾਲ ਲਿਖਤੀ ਨੋਟਿਸ (Written Notes) ਵੀ ਲਿਖੇ ਜਾਣਗੇ। ਮੁਲਾਕਾਤ ਦੇ ਦੌਰਾਨ ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਵਕਤ ਟੇਪ ਬੰਦ ਕਰਨ ਲਈ ਕਹਿ ਸਕਦੇ ਹੋ। ਜੇ ਤੁਸੀਂ ਕਿਸੇ ਪ੍ਰਸ਼ਨ ਦਾ ਉੱਤਰ ਨਹੀਂ ਦੇਣਾ ਚਾਹੁੰਦੇ ਤਾਂ ਨਾਂਹ ਕਰ ਸਕਦੇ ਹੋ ਅਤੇ ਜੇ ਤੁਸੀਂ ਇਸ ਖੋਜ ਵਿਚ ਹੋਰ ਹਿੱਸਾ ਨਹੀਂ ਲੈਣਾ ਚਾਹੁੰਦੇ ਤਾਂ ਵੀ ਨਾਂਹ ਕਰ ਸਕਦੇ ਹੋ। ਤੁਹਾਨੂੰ ਕੋਈ ਵੀ ਪ੍ਰਸ਼ਨ ਪੁੱਛਣ ਦਾ ਪੂਰਾ ਹੱਕ ਹੈ ਅਤੇ ਤੁਸੀਂ ਕਿਸੇ ਵਕਤ ਹੋਰ ਜਾਣਕਾਰੀ ਬਾਰੇ ਪੁੱਛ ਸਕਦੇ ਹੋ।

ਤੁਹਾਡਾ ਨਾਂ ਜਾਂ ਹੋਰ ਕੋਈ ਗਰੁੱਪ ਜਾਂ ਏਜੰਸੀ, ਜਿਸ ਨਾਲ ਤੁਹਾਡਾ ਸੰਪਰਕ ਹੈ ਜਾਂ ਜਿਸ ਦਾ ਤੁਸੀਂ ਹਿੱਸਾ ਹੋ ਉਸ ਦਾ ਨਾਂ ਇਸ ਵਿੱਦਿਆ ਵਿਚ ਨਹੀਂ ਵਰਤਿਆ ਜਾਵੇਗਾ। ਸਿਰਫ ਖੋਜ ਕਰਨ ਵਾਲੇ ਹੀ ਇਸ ਵਿੱਦਿਆ Study ਤੋਂ ਕੋਈ ਵੀ ਜਾਣਕਾਰੀ ਲੈ ਸਕਦੇ ਹਨ। ਇਸ ਵਿਚ ਔਰਤਾਂ ਨਾਲ ਮੁਲਾਕਾਤ ਨੂੰ ਗੁਪਤ ਰੱਖਿਆ ਜਾਵੇਗਾ।

ਇਹ ਵਿੱਦਿਆ ਜਾਂ ਖੋਜ ਵਿੱਦਿਆ ਔਰਤਾਂ ਲਈ ਕੋਈ ਨੁਕਸਾਨਦੇਹ ਜਾਂ ਹਾਨੀਕਾਰਕ ਨਹੀਂ ਹੈ। ਪਰ ਫਿਰ ਵੀ ਜੇ ਕੋਈ ਅਣਜਾਣੀ ਸਥਿਤੀ ਆ ਜਾਵੇ ਤਾਂ ਤੁਹਾਡੀ ਇਜ਼ਾਜ਼ਤ ਨਾਲ ਠੀਕ ਅਨੁਕੂਲ ਰੈਫਰਲ/Referal ਬਣਾ ਦਿੱਤੀ ਜਾਵੇਗੀ।

ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਵਿਚ ਜੋ ਲਿਖਤੀ ਨੋਟਸ, ਟੇਪ ਕੀਤੀਆਂ ਹੋਈਆਂ ਟੇਪਾਂ ਤੋਂ (Transcripts) ਲਏ ਜਾਣਗੇ, ਉਨ੍ਹਾਂ ਵਿਚ ਕੁਝ ਗੁਪਤ ਸ਼ਬਦਾਂ ਅਤੇ ਨੰਬਰਾਂ ਦਾ ਪ੍ਰਯੋਗ ਕੀਤਾ ਜਾਵੇਗਾ। ਜੋ ਲਿਖਤੀ ਜਾਣਕਾਰੀ (Transcript) ਤੁਹਾਡੇ ਨਾਲ ਰਿਕਾਰਡ ਕੀਤੀ ਹੋਈ ਮੁਲਾਕਾਤ ਤੋਂ ਲਈ ਜਾਵੇਗੀ, ਤੁਸੀਂ ਉਸ ਜਾਣਕਾਰੀ ਨੂੰ ਲੈ ਕੇ ਪੜ੍ਹਨ ਦਾ ਪੂਰਾ ਹੱਕ ਰੱਖਦੇ ਹੋ। ਮੁਲਾਕਾਤ ਦੇ ਦੌਰਾਨ ਲਏ ਗਏ ਲਿਖਤੀ ਨੋਟਸ ਸੁਣਨ ਵਾਲੀਆਂ ਰਿਕਾਰਡ ਕੀਤੀਆਂ ਹੋਈਆਂ ਟੇਪਾਂ ਅਤੇ ਹੋਰ ਕੋਈ ਵੀ ਜਾਣਕਾਰੀ ਜਿਸ ਉੱਤੇ ਤੁਹਾਡਾ ਨਾਂ ਹੋਵੇਗਾ-ਜਿਵੇਂ ਕਿ Consent ਫਾਰਮ; ਇਹਨਾਂ ਸਾਰੀਆਂ ਵਸਤੂਆਂ ਨੂੰ ਯੂਨੀਵਰਸਿਟੀ ਆਫ ਕੈਲਗਰੀ-ਫੈਕਲਟੀ ਆਫ ਨਰਸਿੰਗ ਵਿਚ ਸੰਭਾਲ ਕੇ ਤਾਲੇ ਅੰਦਰ ਬੰਦ ਰੱਖਿਆ ਜਾਵੇਗਾ।

ਫੋਕਸ ਗਰੁੱਪ ਤੋਂ ਇਕੱਠੇ ਕੀਤੇ ਹੋਏ ਵਿਚਾਰਾਂ ਅਤੇ ਮੂਲ-ਡਾਟਾ ਨੂੰ ਫਾਈਨਲ ਰੀਪੋਰਟ (Final Report) ਬਣਾਉਣ ਵਿਚ, ਛਾਪਣ ਲਈ (ਪਬਲੀਕੇਸ਼ਨ ਲਈ) ਅਤੇ ਉਸ ਨੂੰ ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਦੀ ਪੇਸ਼ਕਸ਼ ਲਈ ਵਰਤਿਆ ਜਾਵੇਗਾ। ਪਰ ਕਿਸੇ ਵੀ ਸਮੇਂ ਤੁਹਾਨੂੰ ਤੁਹਾਡੇ ਨਾਂ ਨਾਲ ਜਾਂ ਕਿਸੇ ਹੋਰ ਤਰੀਕੇ ਨਾਲ ਤੁਹਾਡੇ ਨਾਂ ਨੂੰ ਨਹੀਂ ਵਰਤਿਆ ਜਾਵੇਗਾ। ਜਿੰਨਾਂ ਵੀ ਸੰਭਵ ਹੋ ਸਕੇ, ਤੁਹਾਡੀ ਜਾਣ-ਪਛਾਣ (Identity) ਨੂੰ ਗੁਪਤ ਰੱਖਿਆ ਜਾਵੇਗਾ ਅਤੇ ਤੁਹਾਡੀ ਪ੍ਰਾਈਵੇਸੀ (Privacy) ਰੱਖੀ ਜਾਵੇਗੀ। ਤੁਸੀਂ ਖੋਜ ਵਿੱਦਿਆ ਦੀ ਫਾਈਨਲ ਰੀਪੋਰਟ (Final Report) ਦੀ ਕਾਪੀ ਲੈ ਸਕਦੇ ਹੋ।

ਇਸ ਫਾਰਮ ਉੱਤੇ ਤੁਹਾਡੇ ਦਸਖਤ ਇਹ ਗਵਾਹੀ ਦਿੰਦੇ ਹਨ ਕਿ ਤੁਸੀਂ ਇਸ ਖੋਜ ਬਾਰੇ ਪੂਰੀ ਤਰ੍ਹਾਂ ਸਮਝਦੇ ਹੋ ਅਤੇ ਇਸ ਵਿਚ ਤੁਹਾਡੇ ਯੋਗਦਾਨ ਬਾਰੇ ਤੁਹਾਨੂੰ ਤਸੱਲੀ ਬਖਸ਼ ਜਾਣਕਾਰੀ ਅਤੇ ਸਮਝ ਹੈ ਅਤੇ ਤੁਸੀਂ ਇਸ ਇਸ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤ ਹੋ। ਇਹ Consent ਕਿਸੇ ਵੀ ਤਰ੍ਹਾਂ ਤੁਹਾਡੇ ਕਨੂੰਨੀ ਹੱਕਾਂ ਤੇ ਲਾਗੂ ਨਹੀਂ ਹੁੰਦੀ ਅਤੇ ਨਾ ਹੀ ਖੋਜਕਾਰ ਜਾਂ ਰੀਸਰਚ ਕਰਨ ਵਾਲੇ ਸਪੌਂਸਰਾਂ ਨੂੰ ਜਾਂ ਇੰਸਟੀਚਿਊਸ਼ਨ ਦੇ ਕਨੂੰਨੀ ਹੱਕਾਂ ਅਤੇ ਪ੍ਰੋਫੈਸ਼ਨਲ ਜਿੰਮੇਵਾਰੀਆਂ ਤੋਂ ਅਜ਼ਾਦ ਕਰਦੀ ਹੈ। ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਵਕਤ ਆਪਣੀ ਸਿਹਤ ਨੂੰ ਖਤਰੇ ਵਿਚ ਪਾਏ ਤੋਂ ਬਿਨਾਂ ਇਸ ਵਿੱਦਿਆ ਤੋਂ ਬਾਹਰ ਹੋ ਸਕਦੇ ਹੋ। ਇਸ ਖੋਜ ਵਿਚ ਤੁਹਾਡੇ ਲਗਾਤਾਰ ਯੋਗਦਾਨ ਦਰਮਿਆਨ ਤੁਹਾਨੂੰ ਪੂਰੀ ਜਾਣਕਾਰੀ ਰਹੇਗੀ। ਜਿਵੇਂ ਕਿ ਸ਼ੁਰੂ ਦੀ Consent ਵਿਚ ਹੈ। ਇਸ ਲਈ ਤੁਸੀਂ ਬਿਨਾਂ ਝਿਜਕ ਕੋਈ ਵੀ ਨਵੀਂ ਜਾਣਕਾਰੀ ਬਾਰੇ ਵਿਸਥਾਰ ਨਾਲ ਪੁੱਛ ਸਕਦੇ ਹੋ। ਜੇ ਤੁਸੀਂ ਹੋਰ ਜਾਣਕਾਰੀ ਚਾਹੁੰਦੇ ਹੋ ਜੋ ਇਸ ਖੋਜ ਨਾਲ ਸਬੰਧ ਰੱਖਦੀ ਹੈ ਤਾਂ ਤੁਸੀਂ ਹੇਠਾਂ ਲਿਖੇ ਨੰਬਰਾਂ ਤੇ ਫੋਨ ਕਰ ਸਕਦੇ ਹੋ:

Nelly D. Oelke
Masters of Nursing
Faculty of Nursing, University of Calgary
Phone: 274-4758

Dr. Ardene Robinson Vollman
Associate Professor
Faculty of Nursing, University of Calgary
Phone: 220-8053

ਜੇ ਤੁਸੀਂ ਇਸ ਖੋਜ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਆਪਣੇ ਹੱਕਾਂ ਬਾਰੇ ਹੋਰ ਸਵਾਲ ਪੁੱਛਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਤੁਸੀਂ **Pat Evans (Associate Director Internal Awards, Research Services, University of Calgary)** ਨੂੰ **220-3782** ਤੇ ਫੋਨ ਕਰ ਸਕਦੇ ਹੋ।

Participant's Signature	**Date**
Researcher and /or Delegate's Signature	**Date**
Witness Signature	**Date**

ਇਸ Consent ਫਾਰਮ ਦੀ ਕਾਪੀ ਤੁਹਾਨੂੰ ਤੁਹਾਡੇ ਰਿਕਾਰਡ ਅਤੇ ਰੈਫਰੈਂਸ (Record of Reference) ਲਈ ਦਿੱਤੀ ਜਾ ਰਹੀ ਹੈ।

UNIVERSITY OF CALGARY

FACULTY OF NURSING

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FOCUS GROUP CONSENT FORM

Research Project Title: **An Exploration of Cervical Cancer Screening Among Women in an Urban Sikh Community**

Investigator(s): **Nelly D. Oelke, Masters of Nursing Student**

Supervisor: **Dr. Ardene Robinson Vollman, Faculty of Nursing**

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this information carefully and to understand any accompanying information.

1. Purpose of the research study and our participation

You are invited to take part in a study. It will look at the views of cervical cancer screening (having a Pap test) of women in the Sikh community. We would like to learn what cervical cancer screening means to women and why they take part in screening or not. We also want to find out how resources and services could best be carried out in your community.

The findings of this research study will give important facts about cervical screening in your community. The information will be used to plan services that will help more women take part in cervical cancer screening over the next few years.

You have been asked to take part because you have shown you are willing to share your understanding and experience of cervical screening. You will be asked to come to a focus group (discussion group) for about 1½ hours. You will only be asked for the time needed for the focus group. A woman who speaks Punjabi will lead the focus group and the researcher will observe the discussions.

2. Your rights as participants

You will be asked if it is okay to tape-record the focus group talk with the focus group leader, observer and the researcher. Notes will also be taken. You can say no to any of the questions and end your part in this research study at anytime. You also have the right to ask questions and ask for more information whenever you like.

Your name or any group or agency that you may be involved will not be used in the study. Only researcher(s) will be able to get any information from the study. You will stay nameless outside of the group that you are part of. Privacy will be kept as much as possible within each group. There are no known risks for women but if at any point in time unexpected situations happen, suitable referrals will be made with your consent.

Code names or numbers will be used on transcripts and field notes. You have the right to get and read a written transcript of the taped focus group that you were part of. Field notes, audio-tapes and any identifying information such as consents will be kept and locked at the University of Calgary, Faculty of Nursing.

Ideas and quotes from focus groups will be used for the final report, publications and presentations of the research information, but at no time will you be known by your name or in any other way. Anonymity and privacy will be assured as much as possible. You may have a copy of the final research report.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at anytime without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact:

Nelly D. Oelke
Masters of Nursing Student
Faculty of Nursing, University of Calgary
Phone: 274-4758

Dr. Ardene Robinson Vollman
Associate Professor
Faculty of Nursing, University of Calgary
Phone: 220-8053

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary at 220-3782.

Participant's Signature	**Date**
Researcher and/or Delegate's Signature	**Date**
Witness' Signature	**Date**

A copy of this consent form has been given to you to keep for your records and reference.

UNIVERSITY OF CALGARY

FACULTY OF NURSING

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FOCUS GROUP CONSENT FORM

Research Project Title: An Exploration of Cervical Cancer Screening Among Women in an Urban Sikh Community

Investigator (s): Nelly D. Oelke, Masters of Nursing Student

Supervisor: Dr. Ardene Robinson Vollman, Faculty of Nursing

ਇਹ Consent ਫ਼ਾਰਮ, ਜਿਹੜਾ ਫ਼ਾਰਮ ਤੁਹਾਨੂੰ ਦਿੱਤਾ ਗਿਆ ਹੈ, ਉਸਦੀ ਕਾਪੀ ਹੈ ਅਤੇ ਇਹ Informed Consent ਦਾ ਇੱਕ ਹਿੱਸਾ ਹੈ। ਇਸ ਫ਼ਾਰਮ ਵਿਚ ਖੋਜ ਜਾਂ ਰੀਸਰਚ ਬਾਰੇ ਅਤੇ ਇਸ ਖੋਜ ਵਿਚ ਤੁਹਾਡੇ ਯੋਗਦਾਨ ਬਾਰੇ ਮੁਢਲੀ ਜਾਣਕਾਰੀ ਹੈ। ਜੋ ਜਾਣਕਾਰੀ ਇਸ ਵਿਚ ਹੈ ਜੇ ਤੁਸੀਂ ਉਸ ਬਾਰੇ ਵਿਸਥਾਰ ਨਾਲ ਜਾਨਣਾ ਚਾਹੁੰਦੇ ਹੋ ਜਾਂ ਜੋ ਜਾਣਕਾਰੀ ਇਸ ਫ਼ਾਰਮ ਵਿਚ ਨਹੀਂ ਹੈ, ਤੁਸੀਂ ਉਸ ਜਾਣਕਾਰੀ ਨੂੰ ਵੀ ਬਿਨਾਂ ਝਿਜਕ ਤੋਂ ਵਿਸਥਾਰ ਵਿਚ ਪੁੱਛ ਸਕਦੇ ਹੋ। ਕ੍ਰਿਪਾ ਕਰਕੇ, ਤੁਸੀਂ ਖੁੱਲ੍ਹਾ ਸਮਾਂ ਲੈ ਕੇ ਇਸ ਜਾਣਕਾਰੀ ਨੂੰ ਧਿਆਨ ਨਾਲ ਪੜ੍ਹ ਕੇ ਸਮਝਣ ਦੀ ਕੋਸ਼ਿਸ਼ ਕਰਨਾ।

1. ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਦਾ ਉਦੇਸ਼ ਅਤੇ ਸਾਡਾ ਯੋਗਦਾਨ:

ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਦੇ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਤੁਹਾਨੂੰ ਨਿੰਮਤਰਨ ਹੈ। ਇਹ ਵਿੱਦਿਆ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੇ ਕੈਂਸਰ ਦੀ ਸਕਰੀਨਿੰਗ ਬਾਰੇ (ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਬਾਰੇ), ਸਿੱਖ ਕਮਿਊਨਿਟੀ ਦੀਆਂ ਔਰਤਾਂ ਦੇ ਵਿਚਾਰਾਂ ਵੱਲ ਧਿਆਨ ਦੇਵੇਗੀ। ਅਸੀਂ ਜਾਨਣਾ ਚਾਹੁੰਦੇ ਹਾਂ ਕਿ ਔਰਤਾਂ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੇ ਕੈਂਸਰ ਬਾਰੇ ਕੀ ਜਾਣਦੀਆਂ ਹਨ ਅਤੇ ਉਹ ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਵਿਚ ਹਿੱਸਾ ਲੈਂਦੀਆਂ ਹਨ ਜਾਂ ਨਹੀਂ। ਅਸੀਂ ਇਹ ਵੀ ਜਾਨਣਾ ਚਾਹੁੰਦੇ ਹਾਂ ਕਿ ਕਿਸ ਤਰ੍ਹਾਂ ਇਹ ਸੋਚਾਵਾਂ ਤੁਹਾਡੀ ਕਮਿਊਨਿਟੀ ਵਿਚ ਪਹੁੰਚਾਈਆਂ ਜਾਣ ਤਾਂ ਕਿ ਵੱਧ ਤੋਂ ਵੱਧ ਔਰਤਾਂ ਇਹਨਾਂ ਸੇਵਾਵਾਂ ਨੂੰ ਪ੍ਰਾਪਤ ਕਰ ਸਕਣ।

ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਦੇ ਸਿੱਟੇ ਜਾਂ ਨਤੀਜੇ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੇ ਕੈਂਸਰ ਦੀ ਸਕਰੀਨਿੰਗ ਬਾਰੇ (ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਬਾਰੇ) ਤੁਹਾਡੀ ਕਮਿਊਨਿਟੀ ਵਿਚ ਮਹੱਤਵਪੂਰਨ ਜਾਣਕਾਰੀ ਦੇਣਗੇ। ਇਹ ਜਾਣਕਾਰੀ ਹੋਰ ਸੇਵਾਵਾਂ ਦੀਆਂ ਯੋਜਨਾਵਾਂ ਬਣਾਉਣ ਵਿਚ ਮੱਦਦ ਕਰੇਗੀ ਤਾਂ ਕਿ ਵੱਧ ਤੋਂ ਵੱਧ ਔਰਤਾਂ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੀ ਕੈਂਸਰ ਦੀ ਸਕਰੀਨਿੰਗ ਵਿਚ (ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਲਈ) ਆਉਣ ਵਾਲੇ ਸਾਲਾਂ ਵਿਚ ਹਿੱਸਾ ਲੈ ਸਕਣ।

ਤੁਹਾਨੂੰ ਇਸ ਵਿੱਦਿਆ ਵਿਚ ਹਿੱਸਾ ਨੈਣ ਲਈ ਕਿਹਾ ਗਿਆ ਹੈ ਕਿਉਂਕਿ ਤੁਸੀਂ ਬੱਚੇਦਾਨੀ ਦੇ ਮੂੰਹ ਦੇ ਕੈਂਸਰ ਦੀ ਸਕਰੀਨਿੰਗ ਬਾਰੇ (ਪੈਪ ਟੈਸਟ ਕਰਵਾਉਣ ਬਾਰੇ) ਤੁਹਾਡੀ ਸਮਝ ਅਤੇ ਜ਼ਰੂਰਤਾਂ ਬਾਰੇ ਵਿਚਾਰ ਸਾਂਝੇ ਕਰਨ ਲਈ ਇੱਛਾ ਰੱਖਦੇ ਹੋ। ਜਾਣਕਾਰੀ ਜਾਂ Data ਆਹਮਣੇ ਸਾਹਮਣੇ ਭੇਂਟ ਵਾਰਤਾ ਨਾਲ, ਇੰਟਰਵਿਊ ਨਾਲ ਇਕੱਠਾ ਕੀਤਾ ਜਾਵੇਗਾ। ਮੁਲਾਕਾਤ ਜਾਂ ਭੇਂਟ ਵਾਰਤਾ ਤਕਰੀਬਨ ਡੇਢ ਘੰਟਾ ਲੰਬੀ ਹੋਵੇਗੀ। ਤੁਹਾਨੂੰ ਦੂਸਰੀ ਮੁਲਾਕਾਤ ਜਾਂ ਭੇਂਟ ਵਾਰਤਾ ਤਕਰੀਬਨ ਪੰਤਾਲੀ ਮਿੰਟ ਲੰਬੀ ਹੋਵੇਗੀ, ਲਈ ਵੀ ਪੁੱਛਿਆ ਜਾ ਸਕਦਾ ਹੈ ਤਾਂ ਕਿ ਰੀਸਰਚ ਕਰਨ ਵਾਲਾ ਲੋੜ ਪੈਣ ਤੇ ਹੋਰ ਪ੍ਰਸ਼ਨ ਪੁੱਛ ਸਕੇ। ਜੇ ਤੁਸੀਂ ਦੂਸਰੀ ਮੁਲਾਕਾਤ ਵਿਚ ਹਿੱਸਾ ਨਹੀਂ ਲੈਣਾ ਚਾਹੁੰਦੇ ਤਾਂ ਮਨ੍ਹਾਂ ਵੀ ਕਰ ਸਕਦੇ ਹੋ। ਮੁਲਾਕਾਤ ਲਈ ਜਿੰਨਾਂ ਵਕਤ ਜ਼ਰੂਰੀ ਹੈ ਉੱਨਾਂ ਹੀ ਵਕਤ ਲਿਆ ਜਾਵੇਗਾ। ਮੁਲਾਕਾਤ ਉਸ ਜਗ੍ਹਾ ਤੋਂ ਕੀਤੀ ਜਾਵੇਗੀ ਜਿਹੜੀ ਸਾਨੂੰ ਦੋਹਾਂ ਨੂੰ ਸੁਖਾਲੀ ਹੋਵੇ ਜਿਵੇਂ ਕਿ ਤੁਹਾਡੇ ਆਪਣੇ ਘਰ ਵਿਚ। ਜੇ ਤੁਸੀਂ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਅਸੀਂ ਦੋਭਾਸ਼ੀਏ/Interpreter ਦੀ ਸਹਾਇਤਾ ਵੀ ਲੈ ਸਕਦੇ ਹਾਂ।

2. ਤੁਹਾਡੇ ਚੱਕ, ਹਿੱਸਾ ਲੈਣ ਵਾਲਿਆਂ ਦੇ ਰੂਪ ਵਿਚ

ਰਿਸਰਚ ਕਰਨ ਵਾਲਿਆਂ ਨਾਲ (ਅਤੇ ਜੇ ਜ਼ਰੂਰਤ ਹੋਵੇ ਦੋਭਾਸ਼ੀਏ (Interpreter) ਮੁਲਾਕਾਤ ਟੇਪ ਤੋਂ ਰਿਕਾਰਡ ਕਰਨ ਬਾਰੇ ਤੁਹਾਡੀ ਸਹਿਮਤੀ ਬਾਰੇ ਪੁੱਛਿਆ ਜਾਵੇਗਾ। ਇਸਦੇ ਨਾਲ-ਨਾਲ ਲਿਖਤੀ ਨੋਟਿਸ (Written Notes) ਵੀ ਲਿਖੇ ਜਾਣਗੇ। ਮੁਲਾਕਾਤ ਦੇ ਦੌਰਾਨ ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਵਕਤ ਟੇਪ ਬੰਦ ਕਰਨ ਲਈ ਕਹਿ ਸਕਦੇ ਹੋ। ਜੋ ਤੁਸੀਂ ਕਿਸੇ ਪ੍ਰਸ਼ਨ ਦਾ ਉੱਤਰ ਨਹੀਂ ਦੇਣਾ ਚਾਹੁੰਦੇ ਤਾਂ ਨਾਂਹ ਕਰ ਸਕਦੇ ਹੋ ਅਤੇ ਜੇ ਤੁਸੀਂ ਇਸ ਖੋਜ ਵਿਚ ਹੋਰ ਹਿੱਸਾ ਨਹੀਂ ਲੈਣਾ ਚਾਹੁੰਦੇ ਤਾਂ ਵੀ ਨਾਂਹ ਕਰ ਸਕਦੇ ਹੋ। ਤੁਹਾਨੂੰ ਕੋਈ ਵੀ ਪ੍ਰਸ਼ਨ ਪੁੱਛਣ ਦਾ ਪੂਰਾ ਹੱਕ ਹੈ ਅਤੇ ਤੁਸੀਂ ਕਿਸੇ ਵਕਤ ਹੋਰ ਜਾਣਕਾਰੀ ਬਾਰੇ ਪੁੱਛ ਸਕਦੇ ਹੋ।

ਤੁਹਾਡਾ ਨਾਂ ਜਾਂ ਹੋਰ ਕੋਈ ਗਰੁੱਪ ਜਾਂ ਏਜੰਸੀ, ਜਿਸ ਨਾਲ ਤੁਹਾਡਾ ਸੰਪਰਕ ਹੈ ਜਾਂ ਜਿਸ ਦਾ ਤੁਸੀਂ ਹਿੱਸਾ ਹੋ ਉਸ ਦਾ ਨਾਂ ਇਸ ਵਿੱਦਿਆ ਵਿਚ ਨਹੀਂ ਵਰਤਿਆ ਜਾਵੇਗਾ। ਸਿਰਫ਼ ਖੋਜ ਕਰਨ ਵਾਲੇ ਹੀ ਇਸ ਵਿੱਦਿਆ/ Study ਤੋਂ ਕੋਈ ਵੀ ਜਾਣਕਾਰੀ ਲੈ ਸਕਦੇ ਹਨ। ਤੁਹਾਡੇ ਨਾਂ ਨੂੰ ਫ਼ੋਕਸ ਗਰੁੱਪ ਤੋਂ ਬਾਹਰ ਬੇਨਾਮ ਰੱਖਿਆ ਜਾਵੇਗਾ। ਹਰੇਕਜ਼ ਗਰੁੱਪ ਦੇ ਵਿੱਚ (Focus Group) ਵੀ ਜਿੰਨਾਂ ਸੰਭਵ ਹੋ ਸਕੇ ਪ੍ਰਾਈਵੇਸੀ (Privacy) ਦਾ ਖਿਆਲ ਰੱਖਿਆ ਜਾਵੇਗਾ। ਇਹ ਵਿੱਦਿਆ ਜਾਂ ਖੋਜ ਵਿੱਦਿਆ ਔਰਤਾਂ

ਲਈ ਨੁਕਸਾਨਦੇਹ ਜਾਂ ਹਾਨੀਕਾਰਕ ਨਹੀਂ ਹੈ। ਪਰ ਫਿਰ ਵੀ ਜੇ ਕੋਈ ਅਣਜਾਣੀ ਸਥਿਤੀ ਆ ਜਾਏ ਤਾਂ ਤੁਹਾਡੀ ਇਜਾਜ਼ਤ ਨਾਲ ਠੀਕ ਅਨੁਕੂਲ ਰੈਫਰਲ (Referal) ਬਣਾ ਦਿੱਤੀ ਜਾਵੇਗੀ।

ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਵਿਚ ਜੋ ਲਿਖਤੀ ਨੋਟਸ, ਟੇਪ ਕੀਤੀਆਂ ਹੋਈਆਂ ਟੇਪਾਂ ਤੋਂ (Transcripts) ਲਏ ਜਾਣਗੇ, ਉਨ੍ਹਾਂ ਵਿਚ ਕੁਝ ਗੁਪਤ ਸਥਲਾਂ ਅਤੇ ਨੰਬਰਾਂ ਦਾ ਪ੍ਰਯੋਗ ਕੀਤਾ ਜਾਵੇਗਾ। ਜੋ ਲਿਖਤੀ ਜਾਣਕਾਰੀ (Transcript) ਤੁਹਾਡੇ ਨਾਲ ਰਿਕਾਰਡ ਕੀਤੀ ਹੋਈ ਮੁਲਾਕਾਤ ਤੋਂ ਨਵੀ ਜਾਵੇਗੀ, ਤੁਸੀਂ ਉਸ ਜਾਣਕਾਰੀ ਨੂੰ ਨੰ ਕੇ ਪੜ੍ਹਨ ਦਾ ਪੂਰਾ ਹੱਕ ਰੱਖਦੇ ਹੋ। ਮੁਲਾਕਾਤ ਦੇ ਦੌਰਾਨ ਲਏ ਗਏ ਲਿਖਤੀ ਨੋਟਸ ਸੁਣਨ ਵਾਲੀਆਂ ਰਿਕਾਰਡ ਕੀਤੀਆਂ ਹੋਈਆਂ ਟੇਪਾਂ ਅਤੇ ਹੋਰ ਕੋਈ ਵੀ ਜਾਣਕਾਰੀ ਜਿਸ ਉੱਤੇ ਤੁਹਾਡਾ ਨਾਂ ਹੋਏਗਾ,ਜਿਵੇਂ ਕਿ Consent ਫਾਰਮ; ਇਹਨਾਂ ਸਾਰੀਆਂ ਵਸਤੂਆਂ ਨੂੰ ਯੂਨੀਵਰਸਿਟੀ ਆਫ਼ ਕੈਲਗਰੀ-ਫੈਕਲਟੀ ਆਫ਼ ਨਰਸਿੰਗ ਵਿਚ ਸੰਭਾਲ ਕੇ ਤਾਲੇ ਅੰਦਰ ਬੰਦ ਰੱਖਿਆ ਜਾਵੇਗਾ।

ਫੋਕਸ ਗਰੁੱਪ ਤੋਂ ਇਕੱਠੇ ਕੀਤੇ ਹੋਏ ਵਿਚਾਰਾਂ ਅਤੇ ਮੂਲ-ਭਾਵ ਨੂੰ ਫਾਈਨਲ ਰੀਪੋਰਟ (Final Report) ਬਣਾਉਣ ਵਿਚ, ਛਾਪਣ ਲਈ (ਪਬਲੀਕੇਸ਼ਨ ਲਈ) ਅਤੇ ਉਸ ਨੂੰ ਇਸ ਖੋਜ ਵਿੱਦਿਆ ਦੀ ਪੇਸ਼ਕਸ਼ ਲਈ ਵਰਤਿਆ ਜਾਵੇਗਾ। ਪਰ ਕਿਸੇ ਵੀ ਸਮੇਂ ਤੁਹਾਨੂੰ ਤੁਹਾਡੇ ਨਾ ਨਾਲ ਜਾਂ ਕਿਸੇ ਹੋਰ ਤਰੀਕੇ ਨਾਲ ਤੁਹਾਡੇ ਨਾਂ ਨੂੰ ਨਹੀਂ ਵਰਤਿਆ ਜਾਵੇਗਾ। ਜਿੰਨਾਂ ਵੀ ਸੰਭਵ ਹੋ ਸਕੇ, ਤੁਹਾਡੀ ਜਾਣ-ਪਛਾਣ (Identity) ਨੂੰ ਗੁਪਤ ਰੱਖਿਆ ਜਾਵੇਗਾ ਅਤੇ ਤੁਹਾਡੀ ਪ੍ਰਾਈਵੇਸੀ (Privacy) ਰੱਖੀ ਜਾਵੇਗੀ। ਤੁਸੀਂ ਖੋਜ ਵਿੱਦਿਆ ਦੀ ਫਾਈਨਲ ਰੀਪੋਰਟ (Final Report) ਦੀ ਕਾਪੀ ਲੈ ਸਕਦੇ ਹੋ।

ਇਸ ਫਾਰਮ ਉੱਤੇ ਤੁਹਾਡੇ ਦਸਖਤ ਇਹ ਗਵਾਹੀ ਦਿੰਦੇ ਹਨ ਕਿ ਤੁਸੀਂ ਇਸ ਖੋਜ ਬਾਰੇ ਪੂਰੀ ਤਰ੍ਹਾਂ ਸਮਝਦੇ ਹੋ ਅਤੇ ਇਸ ਵਿਚ ਤੁਹਾਡੇ ਯੋਗਦਾਨ ਬਾਰੇ ਤੁਹਾਨੂੰ ਤਸੱਲੀ ਬਖਸ਼ ਜਾਣਕਾਰੀ ਅਤੇ ਸਮਝ ਹੈ ਅਤੇ ਤੁਸੀਂ ਇਸ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤ ਹੋ। ਇਹ Consent ਕਿਸੇ ਵੀ ਤਰ੍ਹਾਂ ਤੁਹਾਡੇ ਕਨੂੰਨੀ ਹੱਕਾਂ ਤੋ ਲਾਗੂ ਨਹੀਂ ਹੁੰਦੀ ਅਤੇ ਨਾ ਹੀ ਖੋਜਕਾਰ ਜਾਂ ਰੀਸਰਚ ਕਰਨ ਵਾਲੇ ਸਪੌਂਸਰਾਂ ਨੂੰ ਜਾਂ ਇੰਸਟੀਚਿਊਸ਼ਨ ਦੇ ਕਨੂੰਨੀ ਹੱਕਾਂ ਅਤੇ ਪ੍ਰੋਫੈਸ਼ਨਲ ਜਿੰਮੇਵਾਰੀਆਂ ਤੋਂ ਅਜ਼ਾਦ ਕਰਦੀ ਹੈ। ਇਸ ਖੋਜ ਵਿਚ ਤੁਹਾਡੇ ਲਗਾਤਾਰ ਯੋਗਦਾਨ ਦਰਮਿਆਨ ਤੁਹਾਨੂੰ ਪੂਰੀ ਜਾਣਕਾਰੀ ਰਹੇਗੀ। ਜਿਵੇਂ ਕਿ ਸ਼ੁਰੂ ਦੀ Consent ਵਿਚ ਹੈ। ਇਸ ਲਈ ਤੁਸੀਂ ਬਿਨਾਂ ਝਿਜਕ ਕੋਈ ਵੀ ਨਵੀਂ ਜਾਣਕਾਰੀ ਬਾਰੇ ਵਿਸਥਾਰ ਨਾਲ ਪੁੱਛ ਸਕਦੇ ਹੋ। ਜੇ ਤੁਸੀਂ ਹੋਰ ਜਾਣਕਾਰੀ ਚਾਹੁੰਦੇ ਹੋ ਜੋ ਇਸ ਖੋਜ ਨਾਲ ਸਬੰਧ ਰੱਖਦੀ ਹੈ ਤਾਂ ਤੁਸੀਂ ਹੇਠਾਂ ਲਿਖੇ ਨੰਬਰਾਂ ਤੇ ਫੋਨ ਕਰ ਸਕਦੇ ਹੋ:

Nelly D. Oelke
Masters of Nursing
Faculty of Nursing, University of Calgary
Phone: 274-4758

Dr. Ardene Robinson Vollman
Associate Professor
Faculty of Nursing, University of Calgary
Phone: 220-8053

ਜੇ ਤੁਸੀਂ ਇਸ ਖੋਜ ਵਿਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਆਪਣੇ ਹੱਕਾਂ ਬਾਰੇ ਹੋਰ ਸਵਾਲ ਪੁੱਛਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਤੁਸੀਂ **Pat Evans (Associate Director Internal Awards, Research Services, University of Calgary)** ਨੂੰ **220-3782** ਤੇ ਫੋਨ ਕਰ ਸਕਦੇ ਹੋ।

Participant's Signature	**Date**
Researcher and /or Delegate's Signature	**Date**
Witness Signature	**Date**

ਇਸ **Consent** ਫਾਰਮ ਦੀ ਕਾਪੀ ਤੁਹਾਨੂੰ ਤੁਹਾਡੇ ਰਿਕਾਰਡ ਅਤੇ ਰੈਫਰੈਂਸ **(Record of Reference)** ਲਈ ਦਿੱਤੀ ਜਾ ਰਹੀ ਹੈ।

APPENDIX E—GUIDELINE FOR INTERVIEW QUESTIONS

As interviews will be informal in nature as described by Fetterman (1998), the following questions will be used as a guideline for the interview.

1. Introduce self and the research project.

2. Review purpose of the study and informed consent. We are trying to understand your needs in the area of cervical cancer screening to positively influence changes in resources and services provided in your community. Information collected in the study will be kept confidential and will not be associated with your name.

3. Can you tell me a bit about yourself?
   - When you came to Canada
   - Age
   - Family make-up—here in Canada, otherwise

I would like to ask some questions directly related to cervical cancer screening or the Pap test. May need to describe what the Pap test is.

3. Can you tell me what the Pap test means to you and women in your community?

4. What is the Pap test used for? What are its benefits?

5. What are some of the barriers for women in your community to having a Pap test?

   Possible probes:
   - Barriers to having a Pap test
   - Family aspects
   - Religious/cultural beliefs
   - Beliefs around health in relationship to screening/prevention
   - Importance of the Pap test/priority for the same in their community

6. How do family members influence women in your community about whether or not they have a Pap test?

7. What do you think is the most important reason why women in your community have and do not have Pap tests?

8. Have you had a Pap test before? How long ago was your last one?

9. Additional comments.

APPENDIX F—FOCUS GROUP DEMOGRAPHIC INFORMATION FORM

Code: _____

What is your year of birth? _____

How long have you been in Canada? _____

Language spoken

__ Punjabi only __ Some English __ Speak English fluently

Level of Education

__<grade 9 __Some High School __High School completed

__Some post-secondary __Post-secondary diploma __University degree

Occupation

Do you work outside of the home for pay? __yes __no

If yes what type of work do you do? _____

Do you work part time? __ or full time? __

Please estimate your annual family income?

__ <$20,000 per year

__ $20,000–39,999 per year

__ $40,000-59,999 per year

__ $60,000-79,999 per year

__ $80,000 or more per year

Living arrangements:

__ do you live alone?

__ with your husband and children only

__ with your mother/father-in-law only

__ with your mother/father-in-law and other family members

__ other (please explain) _____

How many children do you have? ___

What are their age groups (Please place the number of children you have living at home in each of the age groups)?

__ <12 years of age

__ 12 years of age and over

Transportation—to attend an appointment, do you normally…?

__ drive yourself

__ take the bus

__ walk

__ have a family member drive you

Physical limitations—do you have any physical limitations that would make it difficult for you to see a doctor for a Pap test (for example use a cane, vision disability, etc.)?

__ yes __ no

APPENDIX G—FOCUS GROUP QUESTIONS

1. Introduction of moderator, observers and the research project.

2. Review purpose of the study and informed consent. We are trying to understand your needs in the area of cervical cancer screening to positively influence changes in resources and services provided in your community. Information collected in the study will be kept confidential and will not be associated with your name.

3. Share main themes uncovered in Phase 1 during interviews with women in the community. This information will be used to direct the questions and content of the focus groups. Possible questions could include the following:

   a) Can you tell me what the Pap test means to you and women in your community?

   b) What do people believe the Pap test is used for? What are its benefits?

   c) What are some of the barriers for women in your community to having a Pap test?

      Possible facilitators:
      - Barriers to having a Pap test
      - Family aspects
      - Religious/cultural beliefs
      - Beliefs around health in relationship to screening/prevention
      - Importance of the Pap test/priority for the same in your community

   d) What advice do you have on how cervical screening resources and services can best be delivered to you and the women in your community?

   e) Additional comments.

APPENDIX H—AUDITOR'S REPORT

Memorandum

Date: October 22, 2002

To: Nelly D. Oelke

From: Ruth Ullman, Auditor

Re: Review of transcripts of interviews conducted by Nelly Oelke

In August 2002, I had the pleasure of reviewing the transcripts of four interviews from the qualitative research currently being conducted by Nelly Oelke.

The four interviews were conducted between November 2001 and January 2002. Two were conducted in English, one was conducted with the use of an interpreter and one used focus group methodology with 18 participants and an interpreter. My main objectives for the transcript review were to evaluate the interviewing process, to code the main themes that emerged and to discuss the themes further with Nelly.

The interviews were guided by general open-ended questions, followed up by specific questions designed to probe for more information. I did not find any evidence of leading questions. Insight gained in earlier interviews was incorporated in subsequent interviews, allowing for a deeper understanding of issues and themes.

Several main themes emerged over the four interviews: the intense privacy surrounding women's health issues in this community, the power and influence of the 'elders' of the community, difficulties with communication between men and women and between generations, the low value placed on preventive health and the extent of the instrumental barriers to preventive health care including language, transportation, and distrust of male community doctors.

In addition, an overarching theme appeared to be the struggle of participants to move from 'inside' to 'outside', where 'inside' represents a tightly guarded traditional society and 'outside' represents the Canadian milieu. Both trepidation and excitement are embodied within this transition and these feelings are reflected in their ambivalent but optimistic view of their ability to learn to prevent cervical cancer.

A follow-up conversation with Nelly in September, 2002 confirmed that she had identified many of the same themes and that her subsequent in-depth analysis of the data has deepened her understanding of the issues.

I appreciate the opportunity to take part in the research, respect the process used and look forward to reading the final discussion of this work.

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