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Date **April 3, 2002**
ABSTRACT

Little information exists about South Asian women's experiences following abnormal cervical screening results particularly within the context of current health care services and structures, and regarding their perceptions of the adequacy of the information, counseling and support provided. This ethnographic study approached this problem by examining South Asian women's descriptions of their experiences of receiving abnormal Pap test results and of their follow-up diagnostic evaluations.

Twelve women, five nurses, and six physicians from two colposcopy clinic participated in the study. Two family physicians from family practice were also included. Data was collected via audio-taped open-ended interviews and journaling. Data analysis proceeded simultaneously with the data collection. The interviews were transcribed and analyzed for common themes.

Obvious issues such as language, cultural values, and beliefs, along with underlying societal, individual and institutional factors that co-exist with health care providers' ability to effectively communicate were described by the participants. Some women believed that health-care providers hold assumptions that stereotype South Asian women. Although some health-care providers attempt to provide culturally sensitive care including the use of professional interpreters and language-specific printed information for women who do not speak English, others lack the resources to provide such care.

In light of these findings, educational approaches are recommended for nurses and physicians that help to raise critical consciousness and foster awareness including the need to pay close attention to diversity and difference. Basic and continuing education that address the importance of individual assessments would enhance nurses' ability to identify women's
individual needs and would help to reduce reliance on stereotypical descriptors of ethno-cultural
groups. Future research to examine discourses in relation to cancer and how language is used
when notifying women about their diagnosis is also recommended.
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THE LITTLE ENGINE THAT COULD. I KNOW I CAN, I KNOW I CAN...!
DEDICATION

To my dear mother who died at the age of forty-nine of breast cancer and to all daughters who have lost their mothers to any form of cancer. To my dear late father who taught me courage and laughter at an early age. To my two beautiful daughters, Sophia and Sonya, I say: "Thank you for being the light of my life. Keep up the courage".
CHAPTER ONE

Introduction

The Papanicolaou smear (Pap) test program was established in British Columbia (BC) in 1949 to screen women for pre-neoplastic lesions of the cervix. If identified early, these lesions can be removed before they develop into invasive cancer. The use of the Pap test has been successful in reducing deaths in BC from cancer of the cervix by 78% in the past 50 years (BCCA, 1999). In BC, over the past 30 years, cervical screening has been effective in reducing the incidence of invasive cervical cancer, mainly squamous cell carcinoma, by 85% (BCCA, 1999). Despite the overall success of this program, cervical cancer rates remain high among some groups of women. Although the British Columbia Cancer Agency (BCCA) does not report Pap smear results by ethnicity, a study done by identifying clients' ethnic backgrounds by their surnames reported that age-specific incidence rates of invasive cervical cancer were 1.5 to 4.5 times higher for South Asian women than for all BC women for each age group above 34 years (Hislop, Mumick, & Yelland, 1995).

Reports by the British Columbia Cancer Agency (2000) indicate that 636,229 cervical and endocervical cancer smears were submitted for analysis for women of all ages in 1999. The Cervical Cancer Screening Program of the BCCA reported the provincial participation rate for women aged 20-69 to be 75% in 1999, a slight increase from the 67% reported in 1998. In this report, 88% percent of women participating had one smear, 11% had two smears, and 1% had three or more smears taken in 1999. Of this number, 1.1% was abnormal with findings of moderate or higher atypia, 7.7% had mild atypia (4.7% new mild atypia), 6.8% had reactive changes, 82.1% were negative or had no atypia seen, and 2.1% were unsatisfactory. The rate of dyskaryosis/dysplasia is highest among women aged 30 and under, at 1.8%, and remains constant at about 1% for over-30 age groups (BCCA, 2000). Although the Pap test is not a
diagnostic test for cervical cancer, the results of about one in every ten Pap tests indicate the presence of atypical cells and merits further investigation. This is a sufficiently large ratio to warrant consideration of the psychological effects of receiving an abnormal Pap test result for all women.

High levels of distress are frequently associated with having an abnormal screening test and undergoing subsequent procedures for diagnosis and/or treatment of the identified problem (Marteau, 1989). Only a handful of studies have investigated women's emotional and psychological reactions to receiving an abnormal Pap test result and to follow-up colposcopies (Kavanagh & Broom, 1997; Lauver, & Rubin, 1990; Paskett & Rimer, 1995; Reelick, DeHaes, & Schuurman, 1984; Wilkinson, Jones, & McBride, 1990). Results indicate that common experiences include fear, anxiety, and disrupted sleep. Researchers have primarily focused on the experiences of mainstream women. Marginalized women who face significant barriers accessing health services may have different experiences.

There is increasing evidence that South Asian women in BC encounter difficulties in obtaining adequate health care. Results of a BC study focusing on European and some South Asian women waiting for a diagnosis after an abnormal mammogram indicate that both groups of women have significant challenges with their health care system encounters when trying to obtain information about suspicious findings (Thorne, Harris, Hislop, & Vestrup, 1999). There is evidence that in Canada, South Asian women's access to Pap testing is not only restricted by their health beliefs, but also by a complex interplay between cultural values and structures within the health care system (Bottorff, Balneaves, Sent, Grewal, & Browne, 2001). One factor that researchers point to is the possible communication difficulties between South Asian women and male health-care providers, particularly in relation to sexual and reproductive health (Bottorff et. al., 2001).
Emerging evidence indicates that some South Asian women are reluctant to seek Pap testing from male physicians. Furthermore, some male physicians avoid topics related to gynecological issues out of respect for women's modesty and comfort (Bottorff et. al., 2001). Given the evidence of psychological distress related to abnormal Pap tests, and that South Asian women and male health-care providers sometimes have difficulties discussing matters related to gynecological health, it is important to explore South Asian women's experiences associated with the receipt of abnormal cervical screening results within the context of current health care services and structures, and to further assess their perceptions of the adequacy of the information, counseling and support provided.

**Purpose and Research Question**

The purpose of this study was to explore and to describe South Asian women’s experiences of receiving abnormal Pap test results and follow-up diagnostic evaluations. This experience includes women's receipt of a Pap test result indicating the presence of atypical cells and recommendations for follow-up diagnostic procedures that may include: (a) Pap smears every six months for two years or (b) diagnostic evaluation by colposcope. The study explored women's experiences in receiving the results of further diagnostic evaluations which may indicate a false positive or a true positive abnormal Pap test, and if required, their response to recommendations for treatments. Furthermore, health care providers’ experiences in providing care to South Asian women in the context of Pap testing and follow-up care will be explored to provide additional contextual information to understand women’s experiences. Women's experiences in receiving treatment for dysplasia or cervical cancer were not included in this study.

The research questions that guided this study were:

1. How do South Asian women describe their experiences with receiving abnormal Pap test results?
2. What are South Asian women's perceptions of their experiences in receiving follow-up diagnostic evaluations, including the adequacy of the information, counseling, and support provided?

3. How are South Asian women's experiences following with the receipt of abnormal Pap test results and follow-up diagnostic evaluations influenced by English-speaking health care providers, and how they are shaped by structures in the health-care system from the perspective of women and health care providers?

This thesis will be organized into several sections. In chapter two, a literature review along with British Columbia Cancer Agency and British Columbia Medical Association’s recommendations for Pap screening procedures for cervical cancer is presented. The methodology used in this study along with data collection and analysis methods is discussed in chapter three. Findings of the study are presented in chapter four including a description of the sample, the general characteristics of the interviews, and the themes arising from the analysis. Finally, chapter five includes a critique of the research methods along with a discussion of the findings and nursing implications.
CHAPTER TWO

Literature Review

A comprehensive search for published literature related to women's experiences with abnormal Pap smears was conducted electronically, using the following databases: Comprehensive Index of Nursing and Allied Health (CINAHL), Psychological Abstracts, Social Sciences Citation Index, Medline and Cancer Literature. Searches were limited to the last fifteen years. Cited relevant literature in published articles was retrieved manually. For the purpose of this literature search, the following key words were used: abnormal Pap smears, Pap smears, cervical cancer, colposcopy, ethnic, minority, culture, and South Asian women.

This literature review is organized into several sections. First, an overview is presented of the British Columbia Cancer Agency and British Columbia Medical Association's recommendations regarding the frequency of Pap smears and the cytology of an abnormal Pap test. Second, a discussion of research findings in relation to women's experiences with Pap smears and abnormal Pap testing is presented. Finally, a review of immigrant women's health care encounters and the concept of culture in the context of health care are discussed. After this discussion, gaps in the literature are identified, solidifying the case for the need to explore South Asian women's experiences associated with receiving abnormal Pap test results and follow-up diagnostic evaluations.

Pap Test Screening and Recommended Follow-up Care

Screening programs have the goal of finding abnormalities in apparently healthy individuals that may be further assessed for malignant potential. The purpose of cervical cancer screening is not diagnostic, but to identify women who are at the highest risk for cervical cancer at an early stage when treatment is more effective, thereby reducing cervical cancer mortality rates. The Cancer Control Strategy Process (CCSP), formed in 1996, currently has three screening programs in place: cervical cancer screening, a screening mammography program, and
a hereditary cancer program. The benefits of cervical screening far outweigh the limitations of the test, making cervical cancer one of the most treatable female cancers if detected early (BCCA, 1999; National Cancer Institute of Canada, 2000).

The Pap test was created as an inexpensive, simple and acceptable method for the early detection of cervical cancer under the World Health Organization's principles of screening for chronic diseases (BCCA, 1999; Robles, 1999). Today, the BCCA and the British Columbia Medical Association recommend that women begin Pap smear screening when they become sexually active or soon thereafter, and stop at age 69 if no significant abnormality is detected during their screening history (BCCA, 1999; BCMA, 2000). If the first three yearly Pap smears are normal, the recommendation is to continue screening at twenty-four month intervals. Although the BCCA (2000) recommend to stop screening at age 69, their reports state that age-specific incidence rates have significantly increased in 1998 for almost all age groups, most notably in the 70+ age group, where the rate has nearly doubled. According to BCCA, it is premature to determine whether this is a new pattern or simply an anomaly, but it is of interest that 46% of the cancer cases in this age group, have not had any Pap smears prior to diagnosis and 42% have not had a smear in the 3 years prior to diagnosis.

The Pap smear is easily obtained by a family physician or by other health-care professionals (e.g., gynecologist, midwife, naturopath, or nurse) during an office examination. A small number of sample cells are removed from around the squamo-columnar junction or the transformation zone in the cervix. These specimens are then analyzed at the centrally located BC provincial pathology laboratory where complete records of results of women's Pap tests and follow-up treatments are maintained. The cytology laboratory makes recommendations for the follow-up of abnormal Pap smears depending on the distribution of the atypical cells. The family physician or other health professional is notified of the results. Generally, a woman is not notified if the Pap smear is normal, although this depends on the physician and his or her
practice. However, in the case of an abnormal Pap smear result, the family physician or other health-care professional usually notifies the woman of the test results and the recommendations for follow-up included in the cytology report. There are a number of ways in which news of an abnormal Pap test result is imparted to a woman. Sometimes it is done over the telephone, at other times during an office consultation; again, this depends on the health professional's usual practice.

Pap Test Results (Normal and Abnormal)

Cervical smears are analyzed to detect dysplasia (disordered growth) around the squamo-columnar junction or the transformation zone in the cervix. The cytology of an abnormal Pap smear is classified into four grades of cervical intraepithelial neoplasia (CIN) (mild-CIN I, moderate-CIN II, severe or high grade-CIN III, and carcinoma-in-situ). In mild dysplasia, only a few cells are abnormal, while in moderate dysplasia the abnormal cells involve about one half of the thickness of the epithelial surface. In severe dysplasia or carcinoma-in-situ the entire thickness of the epithelium is disordered, but the abnormal cells have not yet spread below the basement of the epithelium (BCCA, 1999).

Based on the analysis of cervical smears, the cervical cancer screening program (CCSP) staff divides subjects into two groups: group 1, those that test positive (diagnostic follow-up is required), and group 2, those who test negative or benign (diagnostic follow-up is not indicated) (BCCA, 1999). Each of these two groups contains two subgroups: those who have or will develop cancer, and those who will not. This is illustrated in Table 1.
Table 1

Cervical Screen Results

<table>
<thead>
<tr>
<th>Have or will soon develop cancer</th>
<th>Cervical Screen Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>True negative</td>
</tr>
<tr>
<td>Yes</td>
<td>False negative</td>
</tr>
</tbody>
</table>

Negative or normal Pap smears show typical cells, whereas a common abnormal Pap or a positive result may include inflammation or repair changes, atypia that requires a better sample to categorize, viral changes, dysplasia or invasive cancer (BCCA, 1999). As illustrated in Table 1, negative results indicate that no diagnostic follow-up is required. False negative results pose a concern for CCSP, because in this category subjects may risk developing cervical cancer because of laboratory misclassification (BCCA). When it appears that the sample submitted for analysis may be inadequate, recommendations for repeat smears are made to rule out possible errors. The overall proportion of cases of cervical cancer with a false negative smear for 1997 was 14\(\times\)144 or 9.7%, with an estimated 7% false negative rate for the laboratory component of the cervical cancer screening program (BCCA, 1999). The focus of this study was on women who had received positive test results. This was inclusive of both false positive and true positive cervical screen results.

**Recommendations for Follow-up of an Abnormal Pap Test**

The CCSP follow-up diagnostic test recommendations after a positive Pap smear include six-month interval screening for two years, biopsy or colposcopy at a clinic, or a cone biopsy performed surgically at a hospital. The six-month repeat smear for two years is the most common recommendation for follow-up examinations. As reported by BCCA, mild atypia constituted 93% of all atypia findings for 1998, 92.7% of these cases were recommended for the six-month
repeat Pap smear. Colposcopy is the second most common recommended standard treatment for follow-up examinations (BCCA, 2000).

In 1999, colposcopy was conducted on 4.3% of smears with mild atypia, and 85.5% of those with moderate or higher atypia.

The provincial colposcopy program of BCCA was developed in the 1970s to standardize the investigation used with patients with abnormal cytology. A colposcopy examination of the vagina and cervix is done with a magnifying instrument called a colposcope. The magnification of this instrument permits more accurate identification of the type and extent of the lesion present and helps to ensure that biopsies that are taken are more precise. In 1999, 16,825 colposcopy examinations were provided, 82% of which were initiated because of abnormal cytology reports (BCCA, 2000). The cervix was the primary site of investigation in 95% of the examinations. The CCSP records for 1998-1999 indicate that 75% of women complied with colposcopy recommendations that they received at least one colposcopy examination within 2 weeks to 9 months of being recommended to do so.

**Recommendations for Treatment for Cervical Cancer**

Carcinoma in situ, a pre-malignant lesion on the cervix has a cure rate of 100%. Stage 1 carcinoma that is strictly confined to the cervix is 80-90% curable if detected early with regular Pap tests (BCCA, 1999). Treatment varies according to the results of the biopsy and the severity of the pre-cancerous changes. Cryotherapy (extreme cold or hot) cauterization for dysplastic lesions or cancer in situ, laser therapy (mixture of carbon dioxide, helium and nitrogen gases) to instantly evaporate diseased cells, and loop electro-surgical excision (fine wire loop electrode) used to excise the lesion are usually performed at colposcopy clinics under the guidance of the colposcope. Cone biopsy is used as a diagnostic and a treatment method to remove precancerous changes high up in the cervix (BCCA, 1999). Hysterectomy is used in the case of more advanced
disease or if other gynecological problems are present. Radiation and chemotherapy are used in advanced invasive cancer as adjuvant treatments or when surgery is contraindicated.

**Women's Experiences of Pap Testing**

Beliefs and attitudes, language barriers, socio-economic status and a lack of awareness of the need for regular Pap screening are often cited as barriers to screening among underserved groups. The relationships between illness, everyday life and prevention have been documented in studies of the cultural meaning of cervical cancer as well as in studies of the cultural meaning of illness and chronic conditions (Chrisman, 1981, 1977; Garro, 1988; Kleinmen, 1988). Each individual's experience of health and illness will be different because of important contextual factors influencing one's life including social class, education, and accessibility of health care.

A woman's Pap test experience begins with the initial visit to a clinic, family physician or other health care provider where she has a Pap smear procedure done. At this point, a woman may experience discomfort, pain, and embarrassment or have no complaints at all (Bottorff, et al. 2001; Seow, Wong, Smith, & Lee, 1995). After a waiting period of approximately four to six weeks, if the results are not normal, women are notified of the result and mere recommendations for follow-up diagnostic evaluation from their family physician (See Figure 1). Family physicians are usually responsible for arranging these diagnostic evaluations. Several weeks or sometimes months later, women learn whether their abnormal Pap test is a false positive or a true positive and, in the latter case, what further treatments are required (see Figure 1). Women may have highly distressing experiences while waiting for results a number of times.
Abnormal Pap Test Result Experience

Initial Pap test

British Columbia Cancer Agency

Abnormal result to the family physician or other health care professional

Women contacted about the abnormal Pap test result via telephone, letter or office consultation

Follow-up Diagnostic Evaluations

Repeat Pap test every six months for two years  Colposcopy (diagnostic procedure)

* Results to the family physician

False positive  True Positive

* If at any time an abnormal result is found again the woman is usually referred for colposcopy

Figure 1. Abnormal Pap Test Result Experience

Studies of women's experiences with cervical screening practices have focused on low-income, minority, ethnic and indigenous groups. African-American, Hispanic, First Nations, American Indian, Chinese, Vietnamese and South Asian women including those recognized as new immigrants are among these groups. The research has taken place in several countries. The majority of African-American, Hispanic, and Asian women studied reside in the United States (Baldwin, 1996; Berman, Bastani, Nisenbaum, Henneman, & Crane, 1994; Hoeman, Ku, & Ohl, 1996; Jennings-Dozier, 1999; Kagawa-Singer, 1997; Pham & McPhee, 1992; Yi, 1994). Studies focusing on South Asian women have been conducted in England, Singapore and Canada (Bottorff, et. al., 2001; Fitch, Greenberg, Cava, Spaner, & Taylor, 1998; Hislop, Mumick, & Yelland, 1995; Kernohan, 1996; McAvoy & Raza, 1991; Naish, Brown, & Denton, 1994; Seow et. al., 1995), and studies focusing on First Nations and Native Americans have been conducted
in Canada and the United States (Clarke, Joseph, Descamps, Hislop, Band, & Atleo, 1998; Dechamps, Band, Hislop, Clarke, Smith, & To, 1992; Messer, Steckler, & Dignan, 1999; Strickland, Chrisman, Yallup, Powell, & Squeoch, 1996). Using a number of qualitative and quantitative methods, researchers have explored women's knowledge, attitudes, practices, and experiences in relation to accessing Pap smear screening in a wide range of health care contexts.

For ethno-cultural groups, common barriers to Pap testing include lack of knowledge, fear of pain and discomfort, embarrassment, language barriers, transportation, constraints of time, lack of female health care professionals and negative health care encounters (Bottorff et. al., 2001; Jennings-Dozier, 1999; Kagawa-Singer, 1997; Pham & McPhee, 1992). Although these barriers hinder some women from accessing appropriate health care, researchers also report that cultural beliefs, attitudes and values intersect with gender and social class to influence women's ability to access health care (Bottorff et. al., 2001; Fitch et. al., 1998). Frequently identified factors that enhance access to Pap testing include family support and encouragement, an ability to communicate with the health care professionals in one's own language, culturally diverse educational materials, accessibility of health care facilities in one's own neighborhood, and an availability of child care facilities at the clinics (Bottorff et. al., 2001). In a study that included a small number of South Asian women, personal advice from a general practitioner or a primary doctor was reported to play a key role in women accessing Pap screening (Seow et. al., 1995).

Immigrant women appear to have unique problems in accessing Pap testing. In one study of low-income Canadian women that included new immigrants from Sri Lanka and the West Indies, researchers reported that a major barrier to Pap testing was a lack of physician's recommendations for the test (Fitch et. al., 1998). Many women in this study were unaware of the need for a Pap test because health care providers did not advise women about the screening or its benefits. A few women reported having known their male family physicians for a long
time, and felt somewhat uncomfortable talking with them about a Pap test or having him perform it. Other women thought that the rushed atmosphere in the physician’s office and the answers given without regard to the amount of technical language they contained contributed to the difficulty women experienced talking with doctors. Lack of active participation in health care has also been linked to cultural beliefs and practices, language barriers, financial burdens and experiences of discrimination and racism (Lipson & Meleis, 1985).

Two studies have focused on South Asian women residing in urban settings in Canada and their experiences related to Pap smear access within the Canadian health care system (Bottorff et al., 2001; Fitch et al., 1998). Findings of both studies indicate that women experience difficulty discussing female health concerns and felt uncomfortable in obtaining Pap smears particularly from male health care providers. One woman stated, “I would like a place where I could go and just get it done. My doctor knows me too well. I would like a stranger to do it. It is sort of a degrading position, up in the stirrups and his head down there” (Fitch et al., 1998). Religious requirements for some South Asian women make it inappropriate and improper for them to be examined by men or to remove their clothing (e.g., Baptized Sikhs) (Bottorff et al., 2001; Kernohan, 1996).

Despite some similarities in findings of these studies, it is important to recognize the wide range of diversity among South Asian women. Health-seeking practices and experiences vary depending on women's degree of acculturation, socio-economic status, education level, and health care experiences in their home countries. Furthermore, the influence of structures in the health care system needs to be recognized. For example, in the case of Pap testing, South Asian women's access to cervical screening is not only restricted by their health beliefs and beliefs related to screening, but also by a complex interplay between social class and values, gender preferences, and the structures within the health care system (Bottorff et al., 2001). Researchers report that for many South Asian women asking their family physician for testing was
unthinkable. They were adamant that they did not want internal examinations done by male physicians. Whereas other women who had long standing positive relationships with their physicians reported no gender preferences when accessing Pap testing (Bottorff et. al., 2001; Fitch et al., 1998; Kernohan, 1996).

Specialized Pap test clinics have been established for women of different ethnocultural groups. In Vancouver, the South Asian Pap test clinic offers Pap test screening and breast self-examinations by female South Asian health care providers. Women have provided positive evaluations of the clinic. They appreciated having female staff that could speak their language, the full provision of explanations, and the staff's sensitive approach (Bottorff et al., 2001). The clinic staff, however, did not communicate Pap test results to women. All results are forwarded to women's family physicians who, in turn, share results with their patients and provide follow-up examinations.

**Women's Experiences with Abnormal Pap Smears**

When women receive an abnormal Pap smear result some may experience a range of emotions including anxiety, fear of cancer, changes in body image, concerns about the extent of the abnormal results, and a fear of loss of reproductive functions (Kavanagh & Broom, 1997; Lauver & Rubin, 1990; Rajaram, Hill, Rave, & Crabtree, 1997). The time interval between receiving an abnormal Pap test result and confirmation (or not) of a diagnosis of cancer can be stressful. For example, women waiting for a diagnosis after an abnormal mammogram reported a range of somatic and psychological responses to anxiety, including gastrointestinal upset, tearfulness, and preoccupation with fears (Thorne, Harris, Hislop, & Vestrup, 1999).

Five studies explored women's psychological responses to an abnormal Pap test. Some researchers used self-assessment questionnaires to report women's fear and anxiety to colposcopy treatments (Campion, Brown, McCance, Atia, Cuzick, & Singer, 1988; Carey & Gjerdingen, 1993; Gath, Hallam, Mynors-Wallis, Day, & Bond, 1995; Reelick, De Haes, &
Researchers reported that women experienced psychological side effects such as depression, fears related to the unknown and the need to be fully informed about the possibilities of the abnormal test before screening. These findings indicate the need for appropriate education and counseling following an abnormal Pap test.

Other researchers have used qualitative research methods involving detailed individual and unstructured in-depth interviews to examine women's concerns and emotions following an abnormal Pap test, and women's understanding of the colposcopy follow-up examination (Gath, Hallam, Mynors-Wallis, Day, & Bond, 1995; Hunt, de Voogd, Akana, & Browner, 1998; Kavanagh & Broom, 1997; Lauver & Rubin, 1990; Rajaram, Hill, Rave, & Crabtree, 1997). The most common findings in these studies were women's need for more information about the seriousness of the abnormality and their preference to be examined by female health care providers. Through the use of in-depth interviews, such detailed findings as women's descriptions of how seeing their cervixes on the monitor facilitated their understanding of their abnormality were possible (Kavanagh & Broom). Some women found it difficult to understand what doctors told them because of the technical information in conversations and the material presented during the consultation (Kavanagh & Broom; Hunt et. al., 1998). This research demonstrates the usefulness of qualitative research methods in describing women's health care experiences.

Results from studies exploring women's adherence to follow-up diagnostic recommendations indicate that minimizing the seriousness of an abnormal Pap test by assuaging women's fears interferes with women's adherence to recommended follow-up examinations (Crane, 1996; Funke & Nicholson, 1993; Marcus et. al, 1992; Paskett, Carter, Chu, & White, 1990). Adherence to follow-up recommendations is important in order to reduce invasive cervical cancer, however, most studies exploring adherence have focused on mainstream women.
Research regarding adherence has not considered the effects of this from an ethno-cultural, low socio-economic or minority groups. It is therefore, difficult to draw conclusions about problems South Asian women may encounter in adhering to follow-up diagnostic recommendations (Crane, 1996; Marcus et. al., 1992).

Researchers have explored psychological distress, emotional reactions and women's informational needs related to undergoing a colposcopy (Barsevick & Johnson, 1990; Jones, Singer, & Jenkins, 1996; Marteau, Walker, & Giles, 1990; Massad, Meyer, & Hobbs, 1997; Miller, Roussi, Altman, Helm & Steinberg, 1994; Nugent, Tamlyn-Leaman, Nessim, Reardon, & Crumley, 1993; Tomaino-Brunner, Freda, & Runowicz, 1996). Results indicate that providing some women with appropriate information about the procedure and levels of pain and discomfort to expect may allay some of their anxieties (Marteau et. al., 1990). Other findings suggest that other stresses in a woman's life may contribute to higher anxiety levels at the time of the colposcopy (Nugent, et. al, 1993). Results suggest that education about the colposcopy and the seriousness of the abnormality is more beneficial, when provided prior to visiting the clinic for a further diagnostic examination (Jones et. al., 1996; Massad et. al., 1997).

There are few studies of colposcopy experiences among ethno-cultural populations. Research needs to be directed towards immigrant women who face a variety of barriers in accessing appropriate health care (e.g., language barriers) that may influence their colposcopy experiences and compliance with follow-up examinations (Massad et. al., 1997; Miller et. al., 1994).

**Immigrant Women's Encounters with the Health Care System**

Increases in migration from different countries have posed challenges to the delivery of health care. Evidence shows that verbal communication and interaction between the patients and health care providers can build trust and establish a caring relationship, which may motivate women to return for follow-up examination of an abnormal Pap smear and thereby increase their
chances for survival (Rajaram, 1998). A number of studies exploring immigrant women’s health care encounters indicate women are often marginalized by the mainstream health care structures increasing their difficulty in accessing health care. Results from studies that have examined health care providers’ experiences and their perceptions of working with South Asian women as well as women from other ethnocultural groups suggest that stereotypes and assumptions may exist when health care providers care for women from various ethnic groups (Browne & Fiske, 2001; Bottorff, Balneaves, Sent, Grewal, & Browne, 2001).

A study focusing on Greek and Indo-Canadian women documented that some Indo-Canadian women’s perceptions of Canadian society and how they are viewed in that society influenced their interactions in the health care system (Anderson, 1985). Indo-Canadian women believed that health professionals were unable to understand their problems. For example, when one woman discussed her domestic problems with her physician he told her to “go out and have some recreation.” Anderson (1987) reports that Indo-Canadian women’s perceptions of health professionals arose not only from their constructions of what constitutes a ‘health problem’ warranting professional care, but also from their ongoing experiences with health care providers. South Asian women did not bring their health problems such as loneliness and depression to the attention of the health professionals because women believed they would "not be understood" by health professionals and they attributed their problems to being "different" and unable to "blend in" (Anderson, 1985).

In comparison to South Asian women, Anderson (1987), reported that when most Greek women were not satisfied with the care they received, they would look for another health care provider that was more satisfactory. Generally, South Asian women discussed their problems with family members or friends if they were unsatisfied with health professionals. As Anderson (1985) highlights, solutions that may be acceptable to one group of immigrant women may not be acceptable to or appropriate for Indo-Canadian woman.
Racism and discrimination has also been observed to influence health care experiences of women from ethnocultural groups (Browne & Fiske, 2001; Anderson, 1985). Researchers report that health care professionals are reluctant to inquire about the health behavior of Asian-Islamic women because of a lack of knowledge about their cultural and religious practices (Rajaram & Rashidi, 1999). Evidence shows that women's psychological and physical well being may be compromised by a number of factors such as communication difficulties and experiencing disrespect because of health care providers' ignorance of cultural differences or their stereotypes (Anderson, 1985; Bottorff et al., 2001; Browne & Fiske, 2001; Rajaram et al., 1997).

New immigrants may experience many difficulties related to the immigration experience itself as well as to living in a different culture. These difficulties include a wide range of stressors such as financial burdens, or providing adequate health care for their family members in addition to activities of daily living (Anderson, 1987; Anderson, Blue, Holbrook, & Ng, 1998; Lipson & Meleis, 1985). Observations of elderly immigrant women interacting with care providers within health care institutions emphasized the dependencies experienced when interacting in the "white world" (Dyck, Lynam, & Anderson, 1995). These dependencies were compounded by women's lack of experience outside their own kin-based networks and culturally specific institutions, and their limited English language competency.

The Concept of Culture in the Context of Health Care

Culture has been referred to as the common lifestyles, languages, behavior patterns, traditions, and beliefs that are learned and passed from one generation to the next (Luckman, 1999). In this context, culture is seen as providing a person with specific rules for dealing with the universal events of life—birth, reproduction, childrearing, illness, pain and death. This understanding of culture is limited and can inadvertently perpetuate stereotypes of particular ethnocultural groups. To counter this simplistic view, the issue of health and health care within
the context of culture requires a conceptualization of culture as more than the beliefs, practices, and values of particular groups. Other conceptualizations of culture have been offered. For example, Anderson and Kirkham (1998) locate culture within a constantly shifting "network of meanings enmeshed within historical, social, economic, gender, and curtailment of life opportunities created by environmental and structural inequities" (p. 63). Congruent with this view is Hall’s (1994) conceptualization of culture as a complex and dynamic aspect of individuality, not something static that each member of a community will possess; thus, "culture is a site of convergent interests, rather than a logically or conceptually clarified idea" (p. 522). Thus, by stereotyping or over-generalizing the idea that culture is something that is possessed by some groups, one risks constructing a community as a “cultural minority” or “other” (Anderson & Kirkham, 1998).

In order to keep abreast of the influx of new immigrants, health care providers and policy makers have espoused the concept of multiculturalism, thereby infusing this concept into the health care system in order to try to understand the notion of culture and its relatedness to difference and diversity (Reimer et. al, in press; Browne, Johnson, Botorff, Grewal, & Hilton, in press). Anderson and Kirkham (1998) suggest that “the discourses of multiculturalism, ethnicity, and culture can be marginalizing discourses; the stereotypic, essentializing images produced through these discourses reinforce notions of gendered, classed, and racialized other” (p. 257). The difficulties people encounter in accessing health care and in managing health and illness are often attributed to their cultures and to their differences from ‘mainstream society’, rather than attempting to understand the complexity of factors influencing their experiences or acknowledging the diversity of experiences within ethnocultural groups (Anderson & Kirkham, 1998).

It can be argued that when particular groups are labeled as, “ethnic" or "multicultural", we expect individuals to have common cultural beliefs and values hindering them from accessing
health care as readily as the dominant group. This is probably true to an extent, however, researchers exploring peoples' experiences should also acknowledge the influence of social class, gender, social environment, and the structure of the health care system. Anderson and Kirkham (1998) state, "understanding the meaning of health within the context of culture requires a conceptualization of culture as a complex network of meanings enmeshed within historical, social, economic, and political processes (p. 63)". Therefore, daily life experiences, ways of communicating, ways of constructing meanings from negative or positive occupational experiences and struggles with financial exigencies all influence ethnocultural women's experiences of health and illness (Anderson et. al., 1998; Lipson & Meleis, 1985).

**Gaps in Relation to South Asian Women's Experiences of Abnormal Pap Smears**

A number of Canadian studies have sought to understand South Asian women's experiences with breast and Pap screening practices, their beliefs in relation to health promotion, and their perspectives on health as immigrant women (Anderson, 1985; Anderson, 1987; Bottorff et. al., 2001; Bottorff, Johnson, Bhagat, Balneaves, Clarke, & Hilton, 1998; Choudhry, 1998; Choudhry, Srivastava, & Fitch, 1998). The findings suggest various factors influence access to health care including cultural beliefs, preferences for female health care providers, (especially for gynecological health problems), language barriers, and a lack of knowledge of some health promotion strategies.

Given the understanding of identified barriers that some South Asian women may experience when accessing Pap smear screening, and the psychological distress of receiving abnormal Pap results, research needs to focus on South Asian women's experiences of receiving abnormal screening results and their experiences of follow-up diagnostic examinations. Research needs to focus beyond examining only cultural beliefs and values of South Asian
women that may influence these experiences, to include a focus on the influence of health care structures and processes.

**Summary and Conclusion**

Pap smear screening performed every two years as recommended by BCCA is an effective program in reducing the incidence and mortality rates of women due to cervical cancer (BCCA, 1999; BCCA, 2000). The recommended follow-up diagnostic evaluations and treatments for abnormal Pap tests are necessary in order to prevent invasive cervical cancer. However, as evidenced from the literature, women do not always comply with these recommendations because of a lack of information and knowledge, or inadequate support from health care providers.

A paucity of research describing women's experiences in receiving abnormal Pap test results indicates that women experience high levels of distress. Results document fears related to the possibility of a diagnosis of cancer, loss of reproductive functions, and sexual difficulties. The structure of the health care system, language barriers, opposite-gendered interactions, and South Asian women's cultural beliefs in relation to health care may compound the psychological distress they experience, pointing to the need for further research.
CHAPTER THREE

METHODOLOGY

Introduction

Ethnography is the study of a culture or social group from the perspective of its members. When conducted thoroughly, ethnography has the potential of cultural description that provides detailed portrait of the people under study, thus developing concepts and understanding human behaviors from the insider's point of view (Agar, 1986; Morse & Field, 1995). Culture is not an easy concept to describe, but may be referred to as the acquired knowledge that people use to interpret experience and generate social behavior (Spradley, 1979). However, as discussed earlier in this thesis, the notion of culture in the context of healthcare needs to go beyond simplistic views of culture as beliefs, values and practices of a particular group, in order to explicate the intersectionalities of gender, social, political, economic, environmental and structural inequities in the health care system. Therefore, in choosing to use ethnography as a methodology to conduct this study, the researcher has to be constantly aware of the conceptualization of culture as a process and a set of signifying practices through which meanings are produced. Furthermore, for the purposes of ethnography, the webs of social relations that are established and maintained by individuals in the course of their everyday lives as health care providers and South Asian women accessing health care is critical (Johnson, 1990).

Ethnography is not a new research method, but has a long and distinguished history and has evolved from cultural anthropology. Today, ethnography is broadly used as a qualitative research method as a means of gaining access to health beliefs, values, and experiences of individuals (Morse & Field, 1995). This naturalistic methodology can be viewed as an inquiry into the subjective quality of a social phenomenon in order to interpret and search for social meanings within cultural norms, culturally patterned behaviors, and cultural contexts (Morse &
A central point that should be stressed here is that while there are usually shared beliefs, values, and experiences among people from a given ethnic group, quite often there is also widespread intra-ethnic diversity (Waxler-Morrison, Anderson, & Richardson, 1990).

This research method allows the observer to view phenomena in the context in which the experiences occurred, thus facilitating our understanding of individuals’ health and illness behaviors. Drawing on ethnographic methods to understand South Asian women’s experiences with the receipt of abnormal Pap smears was appropriate in this study, because as Anderson and Kirkham (1998) argue “understanding the meaning of heath within the context of culture requires a conceptualization of culture as a complex network of meanings enmeshed within historical, social, economic, and political processes” (p. 63). Thus, as a researcher, I needed to look at the larger picture of the intersections of social, political, class, health care systems, and the context of the populations’ experiences in order to fully understand how South Asian women accessed health care.

In deciding which research methods to use, particular attention was paid to what the researcher wished to know, the constraints of the setting and sample, and what the expected outcomes of this study were going to be (Hammersley & Atkinson, 1993; Morse & Field, 1995; Spradley, 1979; Wolcott, 1999). The use of ethnography was consistent with the research objectives of this study. Using this method provided the opportunity to develop a rich description of South Asian women's experiences of receiving an abnormal Pap result and follow-up examinations.

**Sample**

The sampling of South Asian women who had received an abnormal Pap test result and were recommended for follow-up diagnostic examinations was limited to the recruitment of volunteers. A similar approach was used to sample health care providers including gynecologists, family physicians, and nurses who provided services to South Asian women.
Although South Asian women include a diverse group of women from the subcontinent (India, Pakistan, Bangladesh, Sri Lanka), East Africa, the Caribbean, Malaysia, or from the Fiji Islands, many South Asian women share similar cultural practices surrounding diet and food, dress, ceremonies, and cultural norms. An effort was made to include volunteers who differed in terms of age, religion, and immigration history. This was done in order to ensure that women with a variety of experiences were included in the research. It was assumed that experiences may differ based on personal, social, and economic factors among women who share similar cultural practices surrounding diet and food, dress, ceremonies, and cultural norms.

Inclusion criteria for this study were (a) South Asian women who spoke and read Punjabi, Hindi, or English (b) informants between the ages of 18-69 years because this age span corresponded to BCCA recommendations for Pap screening, (c), and women who had received the results of an abnormal Pap test from their health care provider with recommendations for follow-up examinations. Efforts were also made to recruit those women who had received an abnormal Pap test result within the last year and had completed their follow-up diagnostic examinations. This strategy helped gain access to women's reflections about receiving an abnormal Pap test result and follow-up diagnostic examinations.

The techniques of purposive and snowball sampling were employed in order to ensure that South Asian women included in the study had received an abnormal Pap test and follow-up examination in a variety of circumstances, and were willing and able to share their experiences (Morse & Field, 1995; Sandelowski, 1995). Attempts in finding women who had delayed following through with recommendations for follow-up and efforts to include women with both false positive and true positive Pap test results were made. As data collection proceeded, the lines of enquiry were refined and major categories were developed (Hammersley & Atkinson, 1993; Spradley, 1979).
Purposive sampling was employed to recruit a sample of health care providers. The selection of health care providers included gynecologists and nurses that provided care to South Asian women during their visits to colposcopy clinics and family physicians in their practice clinics. Health care providers, who provided health services to South Asian as well as women in other populations, were sought to describe their experiences of working with South Asian women and other marginalized groups.

Recruitment

Women were recruited through two colposcopy clinic locations: a colposcopy clinic located at a women's health center and an ambulatory day care centre where colposcopies were performed. Nurse clinicians at the colposcopy clinics identified South Asian women by their surnames. Recruitment was done by employing one of three methods; (a) clinic-nursing staff mailed out invitation letters to women who had been through the clinic for follow-up diagnostic examinations within the last year, (b) clinic staff handed out an invitation letter to South Asian women during their clinic appointments, and (c) through the use of snowball sampling, participants were asked to give invitation letters to other South Asian women they knew who had received abnormal Pap test results. The letter of introduction included the researcher's phone number and contact address, a brief explanation of the project, and an invitation for women to contact the researcher for more information. Once a woman contacted the researcher, the purpose of the study and the nature of the informant's participation in the study were explained. Women were ensured that they had a choice to be involved in this project. Those who agreed to participate signed an informed consent and were then interviewed at a place convenient to them. Privacy and confidentiality were ensured.

Health care providers at the colposcopy clinics and family physicians were recruited by handing out an invitation letter. Those who were interested or had questions were asked to contact the researcher at the phone number on the invitation letter. They were ensured privacy
and confidentiality and were interviewed after agreeing to participate and signing the consent forms.

Data Collection

The ethnographic interview usually involves a conversation in which ethnographers risk the appearance of naiveté and ignorance in order to continually satisfy themselves that they have understood what is being said (Ellen, 1984). Ethnographic data collection methods usually include unstructured interviews and participant observations, but because of the inherent difficulties related to women’s privacy, participant observation was not included in this study. Rather open-ended interviews with South Asian women and health care providers were the primary source of data along with journaling. Reports of both women and health care providers provided rich data related to South Asian women’s experiences of abnormal Pap tests and their follow-up diagnostic examinations. The health care providers were asked to describe their experiences in working with South Asian women who had received an abnormal Pap test result. The advantage of this line of interviewing was to gain further insight into health care systems and practices that influence women’s experiences.

Open-ended Interviews

The ethnographic interview is situated in a social world and is dependent on the interaction between the researcher and the interviewee. It is in this interaction that both participants and interviewers create and construct a narrative version of the social world. Rich descriptions of social worlds are facilitated when friendly conversation is used and where the researcher slowly introduces new questions to assist informants to respond without the awareness of being the participant (Spradley, 1979). Establishing a good rapport between the researcher and the informant is important. Because of the sensitivity of the topic, women were given a choice not to answer a question if they did not want to. Being sensitive to women’s feelings and privacy was important, because this helped enhance rich descriptions of truthful and insightful data.
Some women may have had past negative experiences with health care providers or abnormal Pap test results, therefore paying close attention to their emotional state was very important. Efforts were made to ensure women were comfortable during the interview and at ease, and were advised that the researcher would stop the interview immediately if any emotional problems arose.

Grand tour questions designed to elicit informant's experiences were used (Spradley & McCurdy, 1972). These open-ended questions allowed women to talk of their experiences in a non-threatening manner and to focus on aspects of the experience that were important to them. Furthermore, these questions allowed women to tell their stories in their own way. See appendix “E” for a list of the questions that provided a starting point for the initial interviews.

Two of the twelve women were interviewed twice. The interviews were tape recorded and transcribed verbatim. A total of twelve interviews were conducted with health care informants and these included interviews with gynecologists, family physicians, and nurses. Questions asked of these individuals varied in style, content, and purpose. The clinic staff and the family physicians were asked to describe their experiences in working with South Asian women and their perceptions of how these women seek health care (see Appendix F and G for interview guides).

Journaling in the form of a diary was used to keep track of important impressions and interpretations of things that occurred during the interview process. Descriptions of events or actions of women or health-care providers’ experiences in the colposcopy clinic setting, that did not form part of the unstructured interview, but were short interviews or verbatim texts of words or phrases took the form of field notes along with journal notes. These were later typed up and formed part of the data.
Data Analysis

All of the audiotaped interviews were transcribed verbatim. Punjabi and Hindi audiotapes were translated and transcribed into English by the researcher. A second person checked one interview for correctness in translation and transcription. All the interviews were checked twice to ensure accuracy and correct translation and transcription. Preliminary data analysis began as soon as initial data was collected. The transcribed interviews were read in detail in order to identify important themes in South Asian women's experiences associated with an abnormal Pap test (Spradley, 1979).

Preliminary coding of the interview data was done-line-by-line in order to identify important ideas/experiences (Spradley, 1980). These ideas/experiences were reviewed, noting similarities and differences. Where possible, similar ideas/experiences were grouped into categories. As new data was collected, a similar process was used, revising or adding to the emerging categories as required. Data related to each category was reviewed to identify gaps in the data or inconsistencies that needed to be explored in subsequent interviews and observations. Finally, categories were summarized to identify important themes that described key aspects of the women's experiences. By using constant comparison, contrasting and systematically sifting through the data, the researcher was able to identify relationships between major categories and internal structures of categories (Hammersley & Atkinson, 1993).

Journal entries, which became field notes and formed part of the data, were analyzed along with the transcribed interviews. This helped provide another depth and richness to the data.

Ethical Considerations

There are ethical issues surrounding social research, just as there are with any other form of human activity (Hammersley & Atkinson, 1993). Informed written consent from South Asian women, physicians, and nurses were obtained. Informants were advised that they could withdraw at any time during the study.
Consent forms were translated into Punjabi and Hindi for women who did not read or speak in English. The researcher spoke Punjabi, Hindi and English, therefore was able to communicate and do the interviews in any of the three languages.

Women were advised about their right to refuse to be involved in this research. The informants were advised about how confidentiality and anonymity in relation to the data collected would be preserved. Women were advised that their health would not be influenced by their decision not to participate.

Data including the audiotapes, interviews and field notes, consent forms, and computer disks were stored in a locked cupboard. Access was restricted to the researcher. Informants were not identified by their name at any time of the project. This data will be retained for secondary analysis for future projects.

Women who needed more information about their Pap test results, or had questions regarding their future care were advised to consult with their family physicians. In case women needed advice or counseling for psychological distress related to cervical cancer, they were again advised to consult with their family physicians or the BC Cancer Agency for further support.

Summary

This chapter describes ethnography as the method used in conducting this research study. The selection of informants, data collection strategies and data analysis procedures were described. Ethical considerations that guided the research were explained. Unstructured interviews were used to gather the data for this study. Ethnography with its link to the concept of culture and its use as a means of gaining access to the health practices of a group was an appropriate qualitative method for this study.
CHAPTER FOUR

FINDINGS

Introduction

This study describes South Asian women's experiences of receiving abnormal Pap test results and follow-up diagnostic evaluations. The findings provide insight into how South Asian women make sense of receiving the results of an abnormal Pap test in light of their past experiences and their interactions with health professionals.

The findings have been organized to reflect the themes that were identified in the analysis. Excerpts from the data will be used to illustrate the women's experiences. The chapter begins with a description of the sample and the context of women's Pap test experiences. The next section outlines themes reflecting South Asian women’s experiences: 1) notification of the Pap test results, 2) women’s thoughts on cancer in the context of an abnormal Pap smear, and, 3) the clinical experience of the follow-up diagnostic evaluation. The chapter concludes with a summary of the findings.

Description of the Sample

The sample included South Asian women who had attended one of two colposcopy clinics for follow-up diagnostic procedures following an abnormal Pap test result. A total of twelve South Asian women ranging from twenty-two to fifty-six years of age participated in the study. All except one woman had immigrated to Canada. Nine women immigrated from India; one from England, one from Malaysia and one woman was born in Canada. Years of residency in Canada for the immigrant women ranged from two to thirty-two years. All except one woman spoke Punjabi as a first language. Of the twelve women, eight who were under forty years of age spoke English in comparison to four who were older and did not speak any English. The women represented diverse educational and occupational backgrounds. See Table 2 for detailed socio-demographic data for all women included in the study.
Table 2

Socio-Demographic Data for the Study Sample

<table>
<thead>
<tr>
<th>Age</th>
<th>Birth Place</th>
<th>Years in Canada</th>
<th>Language</th>
<th>Occupation</th>
<th>Number of previous Pap Smears</th>
<th>Age at First Pap Smear</th>
<th>Number of Previous Abnormal Pap Smears</th>
<th>Highest Level of Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>53</td>
<td>India</td>
<td>24</td>
<td>Punjabi</td>
<td>Housewife</td>
<td>2</td>
<td>51</td>
<td>2</td>
<td>(India) Elementary</td>
</tr>
<tr>
<td>34</td>
<td>India</td>
<td>14</td>
<td>Punjabi</td>
<td>Cook</td>
<td>3</td>
<td>26</td>
<td>2</td>
<td>(India) Elementary</td>
</tr>
<tr>
<td>31</td>
<td>Canada</td>
<td></td>
<td>English</td>
<td>Housewife</td>
<td>4</td>
<td>24</td>
<td>2</td>
<td>(Canada) University</td>
</tr>
<tr>
<td>57</td>
<td>India</td>
<td>32</td>
<td>Punjabi</td>
<td>Housewife</td>
<td>3</td>
<td>54</td>
<td>3</td>
<td>(India) Elementary</td>
</tr>
<tr>
<td>56</td>
<td>India</td>
<td>7</td>
<td>Punjabi</td>
<td>Housewife</td>
<td>2</td>
<td>54</td>
<td>1</td>
<td>(India) Elementary</td>
</tr>
<tr>
<td>38</td>
<td>India</td>
<td>15</td>
<td>Punjabi</td>
<td>Seamstress</td>
<td>6</td>
<td>30</td>
<td>2</td>
<td>(India) Elementary</td>
</tr>
<tr>
<td>30</td>
<td>England</td>
<td>22</td>
<td>Punjabi</td>
<td>Computer programmer</td>
<td>4</td>
<td>25</td>
<td>1</td>
<td>(England, Canada) College</td>
</tr>
<tr>
<td>22</td>
<td>India</td>
<td>2</td>
<td>Punjabi</td>
<td>Laborer</td>
<td>2</td>
<td>21</td>
<td>1</td>
<td>(India) High school</td>
</tr>
<tr>
<td>47</td>
<td>India</td>
<td>23</td>
<td>Punjabi</td>
<td>Housekeeper</td>
<td>3-4</td>
<td>43</td>
<td>3</td>
<td>(India) High school</td>
</tr>
<tr>
<td>38</td>
<td>Malaysia</td>
<td>20</td>
<td>Punjabi</td>
<td>Banker</td>
<td>6-8</td>
<td>30</td>
<td>3-4</td>
<td>(Malaysia, Canada) University</td>
</tr>
<tr>
<td>33</td>
<td>India</td>
<td>8</td>
<td>Punjabi</td>
<td>Laborer</td>
<td>3</td>
<td>31</td>
<td>2</td>
<td>(India) High school</td>
</tr>
<tr>
<td>34</td>
<td>India</td>
<td>12</td>
<td>Punjabi</td>
<td>Housekeeper</td>
<td>3-4</td>
<td>30</td>
<td>2</td>
<td>(India) High school</td>
</tr>
</tbody>
</table>

Although ten of the women had previous experience participating in cervical screening, for the remaining participants, this was their first experience with Pap testing. Three women had gone for regular Pap tests every two years; nine received their Pap smear as part of a physical check-up or because of recurring gynecological problems. Of the twelve women, nine had received two abnormal Pap test results after which they were referred to the colposcopy clinic. Three participants received three or more abnormal Pap test results. Two women had been directed for cryotherapy treatment after having received three or more abnormal Pap smears.
All of the health care providers included in this study worked with and cared for women from the South Asian community as well as other ethnic populations. The sample of health care providers included five nurses from two colposcopy clinics, one nurse who worked in a family physician's office, five gynecologists and two family physicians.

General Characteristics of the Interviews

Interviews with all the women were conducted in-person in their homes. After the initial contact was made with the participant, a mutually convenient time was arranged for the interview. At most interviews, there were other family members, such as husbands, mothers-in-law, sisters-in-law, children or grandchildren. Small grandchildren were a distraction sometimes, but most interviews occurred without significant interruptions. The conversation generally began with women inviting me to have some tea and sweets. This helped in establishing an initial rapport and trust with the family and the participant. Often the women and their family members had questions regarding the study. Prior to beginning the interview, I described the purpose of the study and the role the participant would play in the study. After these explanations, the women's written consent to participate was obtained.

The reception I received from family members was generally warm. In a couple of situations, the participants' husband walked in on the interviews, and women had to stop the interviews for a few minutes in order to explain what was happening. In some interviews, the daughter or husband joined in to listen, although it was the daughter who generally participated instead of the husband. This gave the daughter a chance to describe her experiences of being the translator during the health care appointments, which provided important insights into the role of family members as interpreters.

As a researcher, I felt honored that the women openly shared their experiences with me. Meeting women in their homes helped me understand their experiences in the context of their personal lives as South Asian women. This close personal contact gave me important insights
into the women’s lives. Women generally had some other related stories to tell about their health care experiences in their own country, making the interviews interesting. Some women described other related or un-related illnesses and wanted advice about them, because, as they explained, it was easier to talk to someone who spoke Punjabi.

The health care provider interviews were conducted in clinical settings. The gynecologists, family physicians and nurses expressed enthusiasm about the study. They were very co-operative and shared their experiences working with South Asian women as well as with other populations and pointed out some of the similarities and differences between them.

**The Context of Women’s Pap test Experiences**

In order to understand South Asian women’s experiences in relation to the receipt of abnormal Pap test results and their follow-up diagnostic care, it is important to describe the context of their Pap test experiences. Furthermore, it is critical to consider contextual factors such as gender, social environment, and the structure of the health care system that have been identified as influencing how most South Asian women make decisions when accessing health care (Anderson & Kirkham, 1998). Important dimensions of the context of the women’s experiences in this study are described in relation to four themes: the reasons women received Pap smears in the first place, their understanding of Pap tests, and the meaning that the receipt of an abnormal Pap test result had for them in light of their previous health care experiences, and their relationships with their primary health care giver.

**Reasons for Receiving Pap Smears**

Few of the women in this study received Pap tests because they were actively participating in regular screening. Most women received a Pap smear test at the initiative of their physicians in the context of physical examinations, or as part of further investigations in relation to recurring rashes, yeast infections or foul smelling urine. Some participants received their Pap smear from their family physicians, whereas others were referred to gynecologists for screening.
Because most of the women were not aware of the need for Pap testing, they did not actively seek screening. Some of these women received Pap testing only because of the encouragement of their daughters or daughters-in-law who were born and raised in Canada:

Well basically, my daughter told me that I should get a physical done every year because I never had one done before, I mean a physical and a Pap test. Even after I had five kids I never had one [Pap test] done. All the kids were born here and as far as I know I have never had this test [Pap test]. You know, I don’t go to the doctor unless I have a problem, and my daughter told me, I should go regularly to check myself out.

The preceding participant was surprised that a test called the “Pap test” was available, and that none of the health care providers she had visited in the past had ever advised her of the benefits of screening for cervical cancer. Despite the fact that some participants were long-term residents of Canada, who had raised their children in Canada, and had visited family physicians, they knew very little about a Pap test. Participants agreed that most family physicians, regardless of gender, did not offer cervical screening, unless women asked for the Pap test or there were other problems necessitating further investigations.

Some of the women reported that they were referred to female English-speaking gynecologists, when some South Asian male family physicians wanted them to have a Pap smear test. Knowing these women would have difficulties explaining their health concerns due to language barriers, physicians provided letters of explanation that the women were instructed to give to the gynecologist:

The doctor (male family physician) gave me a letter to take with me, and this is what I took with me when I went to the specialist and she [gynecologist] did two tests and then asked me to go to the hospital. My family doctor is the same as for my husband, he [family doctor] is my own kind and he gave me the cream for the rash. It would go away after I used the cream, but it would come back after I stopped using it. He [family doctor]
never checked me for anything, but he just made an appointment and I went to the lady
specialist with my daughter.

There may be several reasons why male family physicians referred women to female
gynecologists for further investigations of women's concerns and Pap testing. Interviews suggest
that most women were referred to female gynecologists out of respect for women's modesty and
comfort with pelvic examinations, whereas other referrals were made to ensure persistent
gynecological problems were thoroughly assessed when women made repeated visits to the
family physician for the problem. However, there were occasions when women were referred to
a female gynecologist just for Pap testing. What is important here is that the women were usually
not given a choice of whether they wanted to go to a gynecologist, or have the family physician
do the necessary examinations. Despite family physicians' good intentions, some women felt
frustrated with the referrals because they had to try and communicate their personal stories again,
to a stranger in English, a language that was foreign to some of them.

Among the women who received regular screening from their family physicians
after their pregnancies, as part of their yearly physical checkup or while they were being
examined for proper placement of an intra-uterine device for birth control, not all were
knowledgeable about the benefits of Pap testing as a test for cervical cancer. Clear explanations
about the benefits of screening were not often provided to South Asian women to make informed
decisions about whether or not to have a Pap smear done. Even when physicians attempted to
provide explanations, women did not always fully understand:

My family doctor, she started doing the test [Pap test] for me and she told me the results.
She told me after I had my baby that I have to do this Pap test. I was so surprised, and I
asked her [family doctor], "What is this Pap test, I don't know about it". She explained to
me, and I said all right, I guess she knows it is best for me, so I get it done. I don't have
to do anything because they [doctor’s office] send me a letter to come in and tell me that
the next Pap test is next month and I make the appointment, otherwise I would forget.

In situations where women lacked a full understanding of Pap testing, respect for physicians' advice provided a strong motivator for women who felt comfortable enough to have a Pap test done by their family physicians.

Although there were seven women over thirty years of age who spoke English, not all understood the benefits of screening. For example, only two participants described an understanding of the need for regular Pap tests. For these women, getting a Pap test meant detecting cervical cancer, at an early stage through regular screening. These two women were young with a university or college level education. They believed they could converse with their family physicians regardless of gender or race and had no difficulty in accessing health care. Their previous health care experiences with their providers lead them to feel comfortable discussing any health care concerns:

Yes I actually went this time to get my IUD taken out, but I go for the Pap test every two years regularly, but this time I went to Iowa for about three weeks and they called and left me a message to come in for a Pap. I have always taken care of myself and especially since I have had my babies, I know that Pap tests detect early cancer and I should have it done, so I am pretty regular. My health is high on my priority list to eat properly, to exercise, and to eat healthy, and take care of myself is always high on my priority list.

It is possible that being able to comfortably communicate with their primary health care givers was an important factor influencing not only their level of understanding of Pap tests, but the way these young women incorporated Pap testing into their health practices. This understanding of Pap tests by some English speaking women and not others, suggested differences in social class, age, and ease when conversing with health care providers; thus displaying differences in construction of similar health care experiences.
Understanding of Pap Tests

Understanding of Pap testing differed among the participants. Some participants lacked information about the benefits of the screening program, and not all comprehended that a Pap test was not a definitive test for cancer. Participants stated they were not always provided clear explanations from their family physicians; therefore they did not fully understand why screening was important in detection. Five of the participants who were referred to female English-speaking gynecologists by their male South Asian family physicians were not given clear explanations about Pap testing by either health care provider.

Communication about Pap testing was more hindered by language barriers and discomfort associated with discussing personal matters for older women in comparison to younger women. Language was seen as a barrier for these older women when they did not speak English, or when some women who were under forty understood English but could not always clearly articulate their questions. Most times, language specific materials or interpreters were not made available to the women during their health care experience. The discomfort some women felt when discussing Pap tests with male South Asian physicians created communication difficulties for physicians as well as women. Some physicians assumed the women did not want to discuss their Pap tests and, therefore, did not provide detailed explanations. Some of the women were embarrassed to discuss their personal problems with male physicians:

I was embarrassed with the doctor and could not tell him everything. And when I went back again for the same thing, then he sent me to the specialist and she is the one who did my Pap test the first time. At that time my son had gone with me because she is a Caucasian doctor and she told my son and my son told me about the problem, but it was hard for him. I went in two times for this test [Pap test] and then after the second time she [gynecologist] sent me to the hospital. It is hard for me even to talk to my own male family doctor; I have to take my daughter-in-law with me, because I get embarrassed.
Communication problems were often multiplied for those non-English-speaking women upon referral to an English-speaking gynecologist even if they were female. Language barriers made it difficult for those women who did not speak English to express themselves: Reliance on male family members (e.g., sons) to act as interpreters created other barriers for both the woman as well as the physician. Sons were uncomfortable discussing personal gynecological issues with their mothers, leading to an incomplete transference of information from the physician to the participant. The women's understanding of their Pap test results was, therefore, not simply a matter of language barriers, but involved a complex interplay of several factors.

Most of the women had a vague understanding of what Pap tests were for, and described it as a test that is "done for cancer." They lacked an understanding of Pap tests as a screening test to detect pre-cancerous cells. By piecing together bits of information about the part of the body that was tested, stories women had heard from other women, and some of the information that physicians provided, most women had a partial comprehension of the reasons for getting screened. Frequently, unsophisticated or lay language was used to describe the Pap test. The following exemplar is a good illustration of how some women described the reason for getting tested:

I did not completely understand. I always thought it [Pap test] was for cancer and to prevent cancer inside women, in the uterus and the breast. Because of the chances of women getting cancer, that is why they do this test [Pap test] and the mammography. They do this test [Pap test] in the place where the baby comes from and they go in with a pipe and check for something, and then they send the specimen and get a report. You know, they do this to find out if there is any disease in that place, like cancer or something.

Almost all of the women recognized that cancer was a dangerous disease that often involved suffering, and some used this information to explain why it is important to have regular
screening. In the preceding exemplar of an English-speaking woman’s construction of her Pap test experience differed from previous exemplars of women who were also in their mid-thirties and spoke English. These different constructions of similar Pap test follow-up experiences among women of one population suggested intra-group differences among South Asian women.

Most health care providers acknowledged that it was not uncommon for some South Asian women to lack a full understanding of Pap smears as part of cervical screening. Some health care providers who worked with diverse ethnic populations believed that in comparison to other women, a larger number of middle-aged South Asian women were unaware of the reasons for screening. The following excerpt from a nurse at the colposcopy clinic illustrates the observation that some women attend the clinic without with full information about the testing procedure:

I think a lot women come here with false expectations that they might have cancer when in fact that is not the case. The information that is coming from the family doctors may not be accurate or what they have heard is different from what is actually going on. I think another thing is that the numbers of women that come in here don’t really know what their cervix is. It actually startles me, and often you know sort of the middle aged ones don’t really know why the Pap test is done. In comparison to the other populations, I think a larger number of the South Asian women are unaware of the reason for doing this test.

Some health care providers assumed that many South Asian women did not have a good understanding of their reproductive systems and about Pap testing and its relation to cervical cancer. Some nurses’ expectations of the extent of most middle-aged women’s knowledge about the location of the cervix were unreasonable. Furthermore, some nurses’ believed that in comparison to the other populations, a larger number of South Asian women were unaware of the reason for screening. Staff at the colposcopy clinics questioned the extent to which
physicians were advising women about Pap tests, and how much information women retained and brought with them to their colposcopy experiences.

**Previous Health Care Experiences**

The health-seeking practices of the South Asian women were influenced by past health care experiences in their country of origin. Previous health care experiences also encompassed women’s perceptions of their relationships with their health care providers, and the roles expected of “South Asian women”. Even though some women had lived in Canada for many years, the women often restricted visits to their family physician to obtain treatment for specific health problems (e.g., pain). One fifty-three year old non-English speaking woman who had immigrated to Canada more than five years ago explained how her decision to see a physician was based on her experience in India:

> When in India, I never used to go to the doctor for anything unless I needed to. Even after I came here, I hardly went to the doctor. I only went if I had an accident at work, like you know if you get a cut with a knife or when I had a fall at work. And you see, this is how it is in India as well, you know, they say everything is going to be fine, and don’t worry and that way there is not much suffering. You know like in India, they can give birth at home and here they check everything like blood and how the heart goes and in India they don’t do these things all the time, only if you have surgery or some big problem. I had a problem with rash that is why I went to the doctor.

It was difficult for some of the women to fully understand the importance of procedures such as monitoring blood pressure, checking for abnormalities in the blood, and doing Pap tests when they were feeling well. Checking “how the heart goes” and “checking the blood” were related to “some big problem or major surgery”. Accordingly, these procedures were viewed to cause anxiety and unnecessary worry for some women.
Some participants as well as health care providers suggested that family physicians play a very important and powerful role in many South Asian women's lives. This is because of the respect that women have for physicians' advice regarding their health, especially in terms of diseases such as cancer. A few women indicated that doctors were "healers" and as such, the advice of the doctor should be followed religiously if one wanted "better health." Some women thoughtfully reflected on the position that doctors have as humanitarians in healing:

The doctor is some kind of God as well and he [doctor] takes care of us and if you don’t eat your medicine, and don’t look after yourself, then how can one get better. You have to believe in God, but one has to follow the doctor’s advice as well. Doctors are here to care for humanity and to look after people, even though it may be in our fate to get ill, but we still have to go to the doctor and listen to the advice.

Spirituality and fatalism came hand-in-hand for some of the women because of their strong belief and values in doctors’ advice and God. A mixture of a few older and younger women voiced such beliefs. This seemed to form a contextual part of these women’s previous health care experiences. For these participants who were both English and non-English speaking, it seemed very important to point out, that although they believed that fate may play a part in their illnesses, their belief in God alone would not get them through these illnesses. Heeding the doctor’s advice was central for these women because according to them physicians knew about healing.

The South Asian women’s family roles influenced their health-seeking patterns. Many women had responsibilities in looking after extended family members. Because of family responsibilities such as dealing with the stresses of managing households, some women suggested they denied themselves the time they needed to care for their own health. Some participants indicated that their dependence on family members for transportation and translation
services limited their ability to access health care services. One participant exemplified the
dependence that some women had on other family members for health related matters:

Well the doctor’s office phoned that the report [abnormal result] had come and to come
whenever I could, but there was nobody home to take me, so I could not go right away. I
went in to see the doctor when I had a ride. You have to rely on other family members,
well most of the time it is all right, but sometimes it becomes difficult when everyone is
working. My daughter took me. She had to speak as well because I don’t always
understand English. Also I had to discuss this test [Pap test] with my husband, you know.

Some of the women's previous health care experiences in Canada included receiving
unclear explanations about their illnesses, and perceptions of being “brushed off” by some
physicians. They stated their physicians “did not always take the time to provide them with
information needed to explain their symptoms”, but rather referred them to yet another
"specialist.” Women suggested that some health care providers stereotype South Asian women,
assuming most do not speak English and know little about their health care. Previous unpleasant
health care experiences with a few health care providers left some women untrusting and
uncertain about accessing health care in the future, as exemplified by this woman’s experience:

I personally think that there should be more doctors taking care of their patients. There
are some gynaecologists out there that don’t explain. I have experienced this and think
that doctors should not take a negative attitude about a patient, whether they are South
Asian or whatever. They should take a positive attitude and help the patient and do every
kind of tests. I have been present in the same room and have heard a nurse talk to an
Indian woman like she doesn’t understand. The nurse is trying to explain something to
her [the woman], but she [the nurse] should realize that this is a full-grown woman and
not a child.
The preceding quote from a thirty-three old woman who had a university level education and spoke English suggested that most women did not have unrealistic expectations of health care providers. They wanted explanations and to be treated respectfully as not only women, but as human beings with emotions. Furthermore, data suggested that providing explanations about Pap tests along with other required examinations, health care providers could increase women’s understanding for screening thus leading to informed decision-making in relation to further examinations.

**Notification of the Pap test Results**

The women interviewed in this study learned about their abnormal Pap test results in different ways. Two women had received abnormal results for the first time; seven had received abnormal results for the second time; whereas others had experienced three or more abnormal results. Most women indicated they were not given clear explanations about their first abnormal result, but were simply called for re-screening by their physician’s receptionist because the first Pap test had been “unclear.” Although most of the women were unaware of the reason for the second screening, they complied with the request for the repeat Pap smear. Fear and anxiety about further examinations and their results were often associated with women’s first abnormal Pap test result. After receiving three or more abnormal results, women indicated they had reduced anxiety because they attributed the finding to persistent minor problems such as rash or yeast infections. A face-to-face consultation when receiving an explanation in relation to the abnormal test result did not seem important to some women. For them, the colposcopy clinic appointment seemed to offer the potential for a solution to the “problems.”

Following the Pap test, seven participants were notified by secretaries to report to the colposcopy clinic for further examinations as part of the recommended follow-up. Although, some of the women did not completely understand the reason for being directed to the clinic, they did follow through with the scheduled appointment without queries:
They did not really tell me that something is wrong, but she [the secretary] told me that I have to go to the women’s clinic. I have to go there [the clinic] and they have instruments to check and machines to go inside and check. She told me I should get this done and then come back to her [the physician’s] office after three weeks.

The limited information provided by secretaries, left some women feeling unsure of what they would find at the clinic. Women were not always given a choice of speaking directly to the physician about the Pap test result. Assumptions appeared to be made that women did not need any information beyond what the secretary could provide.

Some women puzzled over why they did not get better explanations, especially when they had South Asian physicians whom they thought they could communicate with. A few of the women who had South Asian female family physicians who could have provided them with more direct explanations in their preferred language, expressed concern that they were referred to a female gynecologist without having received an explanation from their own physician. These women suggested that assumptions that are formed by health care workers might act as barriers to good communication:

The first time that I had it [Pap test] done, I had gone to her [family doctor] for a full physical check up and she did the test [Pap test]. I did not know about Pap tests before. I just went for a check up and that is when she found this problem [abnormal Pap test]. But when I went back to her she did not tell me anything, she just gave me the letter [for the gynecologist]. Maybe they thought I would not understand, maybe that is why they did not tell me.

Some women believed that some health care providers presuppose that South Asian women do not want full explanations. Because they often do not ask questions about their results, it is assumed that the women are not interested in knowing more about the test results; or that they may not understand or be able to process the information. In light of these assumptions, it
appears that barriers to good communication extend beyond language in interactions between health care providers and South Asian women.

Most women who had South Asian Punjabi and Hindi speaking male family physicians were reluctant to ask questions related to gynecological issues. Although most women did not openly suggest that the gender of their physicians was a deterrent to discussing their questions and concerns related to Pap testing, some women recognized that the gender of their physician influenced their ability to communicate about some health issues. Some women indicated that although they had a male South Asian family physician, it was sometimes hard to openly communicate their problem:

My husband has a male South Asian doctor and if I go to him then I have to lower my eyes if it is something embarrassing about private things, but with women you can say whatever you want, and it is not a problem. You know if our own men are present and we are passing we have to say “sassrikaal” [hello], but to Caucasian we can get away by just saying “hi” and it is not as bad. You can say this is in the culture, and we can’t change it and we have to practice it. It is embarrassing sometimes; because you see among our culture some older women don’t talk to men too much. It is out of respect and it is hard, but you see he is a doctor and this is his job.

Most women from this study thought they would be comfortable talking to female health care providers, and most also felt that it would further enhance communications if they had female health care providers from their community because they would be like “sisters”; thus enabling them to talk more openly than to male doctors.

In comparison to women who did not receive complete explanations, some of the women who went for an office consultation, reported that their physicians took time to explain their abnormal Pap smear result in words they could understand. Of the total number of women who went for office consultations, some were more conversant in English than others, whereas others
did not speak English but took family members as interpreters. Those who were more conversant
had university, college, or high school level education, were younger and felt more at ease with
their physicians.

She [doctor] said that sometimes there is an inflammation and she used the word
inflammation. She said there is nothing to worry about and she [family physician] pretty
well used the word inflammation. She said sometimes there are some bad cells and you
just have to freeze them and she did not use the word cancer at all. The two main words
that I remembered were inflammation and bad cells, but I was still scared until I went to
the clinic and got further tests done. I did not know about the result until I went back to
the doctor’s office in three weeks.

The time that some of the health care providers spent with the participants, along with the
language they used during explanations allayed some fear, although the women still felt anxious
about their visit to the colposcopy clinic for further diagnostic treatment.

In contrast to most women’s descriptions of receiving inadequate explanations about their
abnormal Pap test result despite their desire for full explanations, some health care providers
described in detail their efforts to provide women with full information. They talked about using
diagrams, pamphlets, interpreters, and also encouraging women to bring family members with
them in order to enhance comprehension of the information being provided. However, these
health care providers also suggested there were challenges in providing this information to South
Asian women. They indicated that many South Asian women did not appear to be genuinely
interested in learning more, because they rarely asked questions and often “passively accepted”
directives from health care providers about their abnormal Pap smears and the follow-up
diagnostic care. A female family physician stated:

I must say that the South Asian women don’t ask too many questions. You know it is
amazing. My feelings are that they do not ask too many questions, in a way they are quite
compliant and they basically do whatever you tell them to do, and so just like someone who is quite vague, and they go along with your recommendations usually. I don't know whether this is because of the language barrier or because of their culture.

Some health care providers thought that South Asian women may not want detailed information about the abnormal Pap test, because they already had preconceived ideas that the abnormality equaled cancer. It was also assumed that the stigma surrounding cancer in the South Asian community led most women to avoid talking about cancer. According to the health care providers, some South Asian women did not use the word "cancer" when referring to the abnormality of the Pap test, but rather asked questions such as, "Is it clear?" or "Is there a problem?" One female South Asian family physician provides one explanation:

I do think it is the predominance of families that are not educated because they [South Asian women] don't quite understand. Trying to make them [South Asian women] understand is hard sometimes, because some of the communication shows that there is still a stigma that goes straight to the cancer word. Although I have seen a few people that have spoken English and they just have been anxious people, but I do find that predominantly the people who have the barriers definitely aren't understanding even when we [health care providers] explain to them [women] that the Pap test is a test, they just automatically assume that it is just cancer.

Interestingly, although health care providers assumed that South Asian women did not want to use the word cancer, this was not clearly indicated by the participants. Participants attributed difficulties in communicating with health care providers about Pap tests to fluency in English; some had difficulty speaking English even though they understood it. The women who did not speak English, brought family members with them to medical appointments, but frequently the family members were not fully conversant in the language either.
The two female South Asian family physicians that were interviewed had previously worked in both the Asian and South Asian Pap smear clinics. Both these physicians had been educated in Canada. Data showed similarities between South Asian and non-South Asian physicians' perceptions of how South Asian women access health care and how many South Asian women do not ask questions about their Pap test results. A non-South Asian female physician stated:

Actually they tend to and again I don’t know whether this is cultural they [South Asian women] tend not to ask questions, and that I don’t know whether that is because of the language barrier or because in their [South Asian women] culture. There are different things going on so I don’t know but they vary, the questions in particular.

Similarly, a South Asian female physician stated:

It is surprising to me how some women [South Asian] will not ask about the results. You see, women come from different parts of India as well, and I [physician] have noticed those who do not speak English tend to ask less questions than those who are brought up here. At this office we do Pap smears for women when we do a physical and we tell women that we are doing this test and they usually don’t ask why. I mean I tell them what this is about and if they have heard about, that is my duty.

Both groups of physicians suggested that older as well as some younger non-English speaking women tended to leave decisions about the need for further examinations up to their doctors. One young South Asian female family physician suggested that language is a barrier, but it may be the health care provider’s approach as well as the language makes a difference in women’s understanding:

I think it is the language. Language is a very big thing because the ladies that we want to talk are the middle aged naturally and are not and educated and are staying at home,
because the educated ones are just like all the other women and the other ones are the ones who need to be approached in a non-threatening way and in a friendly way.

However, in comparison to non-South Asian physicians, South Asian female family physicians' perceptions were that South Asian middle-aged women have so many other things to cope with in the context of their family environment that they do not have time to worry about screening:

I think it is both from being a South Asian woman, but having done a lot of locums in a lot of South Asian practices, I have really found that a lot of them they are just dealing with so much at home that even from the other practices other than the Pap test clinics a lot of them just don’t want to have a Pap test, even if I explain it. Even if they were in a male practice and I [physician] was willing to do it and, I noticed that a lot of them are over-burdened and a lot of family things.

Data suggests that female South Asian as well as non-South Asian health care providers had similar experiences working with South Asian women. However, South Asian female physicians in comparison to non-South Asian physicians noted more subtle ‘similarities’ rather than differences. Therefore, although there may be benefits for visiting a female South Asian physician, there may also be disadvantages. It was suggested that assumptions and stereotypes were formed because of educational and social levels between South Asian women as health care providers’ and participants as recipients of care.

Women’s Thoughts on Cancer in the Context of an Abnormal Pap smear

Despite health care providers’ reluctance to focus on cancer when discussing Pap tests, many South Asian women associated Pap testing with cancer. For some participants, mitigating circumstances such as the loss of close family members to cancer or having previous experiences with friends who have been diagnosed with cancer put a different light on the receipt of an
abnormal Pap test result. Most women believed that cancer was an incurable disease, because they had witnessed the struggles and suffering of their loved ones who had cancer. Some women believed that once one has been diagnosed with cancer, it would just be a matter of time before one would die of this disease. These constructions of cancer as a disease were not the same for all women, but differed for women according to age, past experiences with cancer, or knowledge and education women had. Therefore, one young thirty-year-old woman whose mother was diagnosed with cancer referred to the stress, the experience from thoughts about cancer on hearing that her Pap test result was abnormal:

I just felt sick to my stomach and I felt as though it was a lot worse than it was, but for me it was not something that I could shake off my mind, and really until I had the procedure done, I was a wreck up till then, in my mind anyways. I was painting the worst-case scenario and it was a scary place to be. My mother has cancer, so I have always, you know, you start thinking. It made me feel like I was going through the whole thing myself as she was going through, and she is ill and everything at the moment and it really stressed me and kept me from sleeping.

Thoughts about the chances of having cancer were prevalent, and some felt that common sense evaded them at this time, making it more difficult for them to deal with problems that may not have been as stressful at another time.

Issues of living with stigma of cancer troubled some women and led them to believe that an abnormal Pap test was something that needed to be kept private and hidden within the close family circle. Beliefs around the possibility that daughters of mothers with cancer could have this disease as well created uneasiness for the family. Women suggested that having cancer would discredit the family in the eyes of the community; thus the thought of receiving an abnormal Pap smear and its relation to cervical cancer made some women feel anxious. Accordingly, some
young as well older women did not want to openly discuss the results of their Pap test with others:

I never talk to anyone about this and do not talk to other women about this either. Maybe if I can’t take it anymore, and need help then I will. Otherwise I don’t usually talk to anyone else. And even my daughter-in-law, it took me a long time to talk to her. Even taking someone else with you to the doctor, some woman friend, I feel strange and think what if she tells other people in the community about this [test]. If she tells her mother-in-law then other women might find out. But I have to take someone because I don’t speak English. This is not a good disease and I know other women who have small children and the doctor has told her she is going to die. Her mother-in-law takes care of her and the children.

Some women believed that in order to decrease the chances of getting cancer, it was important to follow through with recommendations about screening from their physicians. Many women believed that fate played into everyone’s life, but that fate does not always have to be accepted. Taking care of oneself is one thing a woman can do to stay healthy:

We all have to go to the doctor because of our health and the needs of our body, to keep it healthy so that our lives are better. But you know as soon as you hear cancer, you know that you cannot be saved and this can happen within three months, six months or ten years, nobody knows about this, not even the doctors. I know some woman who has cancer and she has little children and her doctor has told her that she can go today or tomorrow, and she has lost all her hair and everything. I went to see her and she feels alone because she feels like she cannot always share her thoughts with anyone else.

Although most women did not fully understand what an abnormal Pap test was and the reason for regular screening, they believed it was important to keep themselves healthy by visiting the family physician when they experienced changes within their bodies and for checks like Pap
testing. Some women felt that nothing could be done once women had advanced cancer, but if other women knew more details, they might go for screening.

The Clinical Experience of the Follow-up Diagnostic Evaluation

The two colposcopy clinics that the sample was recruited from differed in the structure of their physical environment and the information that was provided about clinical procedures. These differences had a direct impact on the women’s experiences at the clinics. Most women attending one clinic described experiences that reflected a lack of respect and privacy and attention to women’s modesty. For example, the women recalled having to sit in the waiting room among other people dressed in street clothes, while they were attired in hospital gowns. Participants shared they felt “very naked” and “embarrassed” with their legs exposed, especially because of their South Asian upbringing. One woman shared her experience, hoping that something could be changed at a later date:

I was in this hospital gown and there were other people sitting in front of me that were not in hospital gowns, so you felt kind of weird. There was another woman I think that was going in for something similar to me, because she had a hospital gown, but other people were wearing normal street clothes. You know you are sitting there in this skirt type of thing and you have nothing on the bottom because they ask you to take off your underwear. Even though you have a gown covering your back it just kind of feels weird. I am really a shy person, you know. When it comes to the upbringing you know the East Indian upbringing, I think it may be a little different from other women.

The participants also recognized that their discomfort with sitting in the waiting room was not one based exclusively on ethnic background, but that most other women who came to the clinic had to do the same and that they may have felt similar emotions.

Interestingly, nurses at this clinic acknowledged that South Asian women attending the clinic were not entirely comfortable with their visit. They noted that South Asian women were a
little more reserved than other women, and did not ask too many questions about procedures. The nurses also suggested that although women followed directions, their body language and behaviour showed signs of discomfort. One nurse stated:

Most women come in and they sit down with their arms folded into their seats when you go to do the interviews and you can tell they are anxious. They will sit in the waiting area watching the patients who have just had a procedure done come out. And you see some South Asian women when they go for their turn, they are clutching their gowns close to them and you can see they are uncomfortable. Sometimes some of them will sit in the cubicle because they don’t want to be sitting in their gown even though we give them two gowns. I think this is because there are other people in the waiting room including some South Asian men as well.

In contrast, women who visited the women-centred colposcopy clinic appreciated being able to wait in an area with the curtains drawn. This clinic also offered women detailed information and a video presentation of the procedure, along with a short interview with the nurse. The interview and presentation of the video were done in the privacy of a room. Participants in this colposcopy clinic experienced a more relaxed environment, and believed that the clinic was suited to women’s needs. The following participant who visited this clinic reflected that she felt at ease the minute she walked through the door:

I was painting the worst-case scenario. I think in my mind, I was going to the scary place. They [health care providers] are going to look inside me. I think it was because of that being in my mind that it felt so bad, but it ended up being so good really. I couldn’t say that the whole clinic experience was pleasant because it is unpleasant having some one do this procedure anyways. Just the attitude of the people there and the video there made me feel like I wasn’t the only person there for this and did not feel lonely or totally alone and it was a friendly atmosphere. Some women had brought friends as well.
In the women-centred clinic, women were screened for the need of translators at the time of the initial appointment, and an interpreter was present when language was identified as a barrier to the receipt of health information. Interestingly, the other clinic, which had the higher demand for language specific services, did not always provide interpretive services. Thus the onus for translation often fell to family members, regardless of their fluency in English. Although most of the time health care providers used family members as interpreters, they preferred professional interpreters rather than family members, even though they recognized that not all South Asian women were comfortable with the use of professional South Asian interpreters as the following exemplar illustrates:

I find that the family member does not adequately deliver the information and will slough off information and won't advise women of the procedure. They will only repeat it after we ask them to. The family member would usually say that is ok, they understand. But we see that it is not ok, because we can see that there is no acknowledgement from the women as to what we are going to do. We don’t understand what they have told the women anyways. You know maybe they don’t understand it all either, and if there is a son who has come with his mother, it is hard for them. Another thing is that some South Asian women do not like to talk to professional interpreters who are from their own culture. I find that they won’t ask any questions, but will only listen.

Health care providers acknowledged that the personal and complex relationships that families have with each other influence their ability to be effective interpreters, especially about sensitive health matters. In addition, when family members do not understand all the information themselves, translations are further compromised. On the other hand, when professional interpretative services were provided by female interpreters, who were well versed in the health care system, some South Asian women were believed to be uncomfortable using their services.
There was a lack of trust on the participant’s part that confidential information about their health would be “leaked out” into the community by South Asian interpreters.

Issues related to providing interpretative services were important because most of the health care workers at the two colposcopy clinics were English speaking. Usually nurses provided explanations and directions in English and the gynecologist talked women through the procedure in English. The women understood varying amounts of these explanations, however, limited fluency in English decreased their ability to actively interact with health care providers:

Yes it would be easier to understand if there was somebody who spoke Punjabi. It was not that difficult to understand in the room because they told me to go onto the bed, but if there was any [information] more than it would be hard to understand this. I understood him [physician], but it would be hard for me to say anything back and I would need somebody to say something for me if I need to talk to them [health care providers].

Most women felt that even though the follow-up procedures were not complex and did not take long, there still needed to be language specific information provided by the health care worker in case the participants had questions during the procedure.

Most women’s clinical experiences fell short of their expectations. Although women appreciated the gynecologist advising them there was “no cancer”, some women felt the doctor could have been “a bit more caring and used a more pleasant tone of voice and choice of words” when delivering the information about the colposcopy. They expected health care providers to take time to explain the colposcopy procedure and its results:

I was relieved because the doctor told me right away, but I must say that he did not say it in a very nice way, he just said, “no cancer”. I mean I would have liked somebody to say, “I have taken a look and everything seems ok and there doesn’t seem to be any cancer”; I mean a little more elaborate. It was his tone of voice and it was exactly how he said it. After he [gynecologist] had finished he said, “I am going to put a tampon”, and I said,
“well I don’t use a tampon, I have never used one”. The nurse then gave me a pad and she was very nice. And after he had finished, he stood up and he went to the other side of the room. He talked with his back to me, and when I got off the bed and straightened my gown and asked if everything was ok, he said, “don’t worry, there is no cancer”.

This exemplar illustrates the possible consequences of a focus on efficiency during clinical procedures. When the focus was on moving patients through the clinic, there was little time to recognize and respect women’s preferences for care. The woman in the previous quotations did not have unrealistic expectations. She wanted the physician to explain the results of her colposcopy and to be offered choices (e.g., tampons or pads). Her clinic experiences led her to wonder if she was treated differently than other women, because she was South Asian.

Other women spoke of simple things that would have enhanced their clinic experiences. Although at the women-centered clinic all clients were given a sheet as a drape for covering their legs while the procedure was being done, draping was not done routinely at the other clinic unless women made a specific request:

I guess that is the only room that they have to perform these things or whatever, and that’s how they have to do it and the practice of giving you an extra sheet to put over your legs would be nice. There was something that was cold, I don’t know if the room was cold or something he inserted was or something, but it could have a bit of a warmer feeling and when the speculum goes inside you it is cold and a sheet over you would be nice. It seems that they do the same for all women, so they all should do something.

The women felt they could not voice their desires in how they should be cared for during these procedures. Some participants wondered whether some health care providers thought of women coming in for examinations as people or objects. Some health care providers at this particular clinic created no familiarity or comfort.
But just the way that I was just sitting there and I just had something done and I mean I feel, it is a very personal part of you, and I hate the position you have to sit in and everything. It made me feel like he is just doing his job and he has no emotion in it what so ever. I am a person and he checked me in the most private part that a woman can have. The feeling of being objectified was further illuminated in the preceding exemplar, when the participant’s observation led her to believe that the physician was doing his job rather than working with women who had emotions.

**Summary of the Findings**

South Asian women who participated in this ethnographic study differed in age, education, fluency in English, and the number of years they have had lived in Canada. Most women received a Pap test either in the context of a physical check-up or because they sought medical advice about other gynaecological problems. Few participated in regular screening. The context in which South Asian women received Pap tests was discussed in relation to the receipt of abnormal results. Interpretation of the data provided insight into how South Asian women perceived their experiences of the receipt of their abnormal Pap test results and their follow-up diagnostic care. Women's thoughts on cancer, their clinical experience of the follow-up diagnostic evaluation, and the various ways in which women were notified about their abnormal Pap test results were discussed. The findings of this study underscore the complex factors that are at play when English-speaking health care providers along with South Asian male and female physicians provide health care to diverse ethnic populations and how language is not the only barrier that most health care professionals as well the South Asian women have to overcome.
CHAPTER 5
DISCUSSION

Introduction

The findings of this study add to existing knowledge in relation to multiple factors influencing South Asian women’s health care encounters at both individual and institutional levels. The study describes South Asian women’s experiences of receiving an abnormal Pap test result and their follow-up diagnostic evaluations. Women’s perceptions of their experiences in a clinical setting providing follow-up colposcopy procedures are described as well. An examination of the data provided a window into analyzing how gender, health care providers’ assumptions, and culture influenced how South Asian women received Pap tests and were later notified about their abnormal Pap test results. The results may not be generalizable to all South Asian women, but they do raise questions for further research.

In this chapter, significant findings will be discussed in light of relevant research to further illuminate existing knowledge of South Asian women’s experiences in the health care system. Measures taken to ensure rigor, and the strengths and limitations of the research methodology will be discussed in relation to the findings of this study. Finally, the significance and implications of these findings are discussed in regard to nursing practice, education, and research.

Brief Summary of the Findings

South Asian women’s experiences of abnormal Pap test results and follow-up care are reflective of the initial reasons they received Pap tests, their understanding of cervical screening, and their previous health care experiences including their relationships with health care providers. Issues related to the quality of care provided to South Asian women and the complexity of providing cross-cultural health services serve as overarching themes in the
findings. Most participants received Pap tests from their family physicians, or were referred to gynecologists after visiting their family doctors for other gynecological problems. The women’s understanding of Pap tests was often compromised by language barriers, the provision of written material in English, or health care providers’ failure to provide clear or detailed explanations. Barriers were also created by prior negative health care interactions. The women’s sense of being “brushed off” by some physicians was attributed to physicians’ assumptions that most South Asian women did not want explanations because they did not ask questions.

Women’s responses to thoughts about cancer in the context of abnormal Pap tests included fear and anxiety. Some participants had lived vicariously through other family members’ experiences of cancer and this heightened their fears about cancers when they received abnormal Pap results. Most participants thought that interpreters should be provided for those who were non-English speaking, and that more complete information would enhance their understanding of abnormal Pap test results and follow-up procedures. Despite health care providers’ efforts, some health care interactions that surrounded the receipt of an abnormal Pap test fell short of most women’s expectations. The women identified several ways that health care services could be improved. A discussion of these findings will further illuminate South Asian women’s experiences and strategies for providing more culturally sensitive and individualized health care will be proposed.

Reflections on the Research Methods

Ethnography proved to be an effective means of studying the phenomena under investigation in this study. This qualitative research method facilitated a contextual understanding of the identified problem by allowing the data to be interpreted through a “cultural lens” (Agar, 1986; Spradley, 1979; Hammersley & Atkinson, 1993). A central argument here for an ethnographic approach is that women’s everyday experiences as well as their health care experiences cannot be attributed solely to their ‘cultural differences’, but must also be
understood within the context of the larger social organization of health care structures. Although the sample of women in this study ranged in age, number of years of residency in Canada, and the number of Pap tests they had received along with the abnormal results and follow-up evaluations, they shared some similarities in their health care experiences that reflect commonly held beliefs and values, and the influence of social structures such as gender.

Differences between qualitative and quantitative research methods make it inappropriate to use the criteria of reliability and validity used in quantitative research when evaluating qualitative research. A set of four criteria including credibility, fittingness, audibility, and confirmability were therefore used to assess rigor in this study (Sandelowski, 1986, 1993). The strategies used included a clear decision trail for auditability through journaling and notes; checking and re-checking the translation and interpretation of the interviews for credibility; and constant analysis of the incoming data and respondent validation to maintain confirmability. Finally, a process of critical reflexivity by the researcher in order to bracket possible biases was employed to strengthen rigor in this ethnographic study. I attempted to identify my pre-conceived notions of South Asian women's cultural and ethnic backgrounds, and their beliefs and values. I examined the data to these bracketed assumptions and attempted to view the data as an outsider rather than an insider.

Multiple methods of data collection included in-depth interviews with women and health care providers, journaling, and field notes. Most of the interviews were done in Punjabi and then translated and transcribed into English by the author. All the interviews were checked line-by-line for accuracy. Another person checked one Punjabi interview for accurate English translation and interpretation. Field notes and journaling were used to record the decision trail taken by this investigator and allowed the process and logic of all decisions involved in conducting this research to be evaluated by others.
It is recognized that the absence of participant observation as a supplementary method of data collection is a limitation of the study. Although it is understood that participant observation would have provided an added dimension to the data (Agar, 1986), the investigator did spend several days in both colposcopy clinics as an observer. These clinical observations included following the nurse and the physician in order to increase the investigator’s understanding of the clinical procedures and the experiences women shared in interviews. Clearly, participant observations rather than clinical observations would have strengthened this study by allowing the researcher to conduct systematic and detailed observations over a longer period of time. The simultaneous collection of data and analysis would have focused on observations and provided direction for conducting in-depth interviews.

Follow-up interviews were not done as extensively as planned, but the two that were conducted proved to be valuable for validating findings and interpretations. Member checking to validate and extend findings was done by asking the informants to comment on preliminary findings. The two women, who participated in the second interviews and reviewed a summary of the findings, were unanimous in acknowledging that these findings reflected their experiences.

Constant analysis of the incoming data and modifying interview questions to elicit more in-depth data of South Asian women’s experiences helped to ensure confirmability. As a South Asian investigator doing this study, the researcher had to bracket her biases in relation to South Asian women and their experiences in accessing health care (Sandelowski, Davis, & Harris, 1989). This was accomplished by examining pre-conceived assumptions about South Asian women’s health care practices, personal beliefs and values. By identifying and examining pre-conceived ideas, and comparing these ideas to the data, the researcher attempted to minimize the influence of her biases in interpretation of the data. In addition, the investigator recognized that being a South Asian woman had specific advantages. I was granted insider status due to my ability to speak Punjabi as well as Hindi and also because I was considered part of the
community. Throughout data collection and analysis, I was continually challenged to reflect critically on my own assumptions, cultural beliefs and stereotypes and their influence on my interpretation of the data. Through a process of reflexivity and innovative discernment, I experienced a shift in understanding during the final stages of data analysis. This was documented by voluminous writings that preceded the final interpretation, correspondence with mentors, and multiple attempts of analysis.

To some extent, the relatively small number of interviews conducted for this study may be a limiting factor. However, the diversity of South Asian women, nurses, gynecologists, and family physicians interviewed enabled the author to sift through both the participants’ and health care providers’ experiences to identify and examine differences and similarities among the participants’ experiences. Nevertheless, the diversity of South Asian women’s experiences may not be fully captured in the study. Although it is acknowledged that this is by no means an exhaustive study, the findings provide valuable insight into South Asian women’s health care experiences and have implications for certain aspects of practice, education and future nursing research.

**South Asian Women’s Experiences of Abnormal Pap Test Results**

The findings indicate that most of the women were concerned about the receipt of an abnormal Pap test result. Some of the women experienced anxiety around the seriousness of the abnormal results and the possibility of having cancer, whereas others interpreted the results to be a part of the diagnostic procedure in eliminating other minor gynecological problems. Others have reported that women feel nervous, fearful, or upset and express concerns about the seriousness of the implications of abnormal findings (Lauver & Rubin, 1990; Hunt, de Voogd, Akana, & Browner, 1998).

Variations in the amount and type of information provided in explanations related to an abnormal Pap test revealed in this study may be an important factor influencing women’s
responses. Most women referred to the result as “the problem” or “something is wrong”, while others used medical terms (e.g., “abnormal Pap test”). Some of the women questioned the physician about implications of an abnormal Pap test result, whereas others accepted the explanation given by their family physician even when they may not have fully understood the meaning of the results. The women in this study tried to make sense of the results in different ways. Their explanations of the abnormal test results did not always correspond to medical opinions or views. Kleinman (1988, 1978) suggests that the differences in explanations of health and illness stem from how individuals make meaning and understand their experiences.

Most women’s explanations about the procedure of the Pap test differed as well. Important factors that appeared to influence women’s explanations were fluency in English, previous health care experiences, and education. Health care providers indicated that not all women fully comprehended the anatomy of the body and suggested this contributed to their inability to comprehend abnormal test results. This interpretation is supported by Hellmann (1994). He suggests that for most people the inner structure of the body is a matter of speculation and without the benefits of x-rays and photographs, where one can see an organ or where the pain is located, beliefs about how the body is constructed are usually based on inherited folklore and influences of people’s perception of bodily complaints. Furthermore, the importance of this ‘inside-the-body’ image influences people’s perception and presentation of bodily complaints, and their responses to medical treatment.

Reports from some of the health care providers suggest that South Asian women were expected to share similar responses to screening and abnormal Pap test results as most mainstream women. However, the health care providers recognized that other factors such as social values, personal health care beliefs, family structures, and previous negative or positive health care experiences influenced South Asian women’s decision making about screening and recommended follow-up evaluations. Thus, it is important to recognize that although these
findings are corroborated by other similar studies (Lauver & Rubin, 1990; Hunt et. al., 1998), there appears to be a general lack of recognition that every South Asian woman is different in how she constructs meanings of health and illness. Todd and Fisher (1993) take it a step further and argue that although most women’s experiences may be similar in some ways, there are differences in how they perceive medical practitioners.

Health-Care Communications with Diverse Ethnic Groups

As part of the health care system, nurses constantly face challenges working with ethnic populations. Challenges include finding ways to communicate effectively, build and maintain relationships with clients, and provide care and support to individuals with differences that may be unique to them. The trend in recent years has been to provide culturally sensitive care for ethnically diverse populations by varying plans of care for ethno-cultural groups. In today’s health care system, culturally sensitive care is broadly defined as the delivery of health care through recognition of differences between diverse populations. Most health care providers in this study believed they delivered culturally sensitive care when they paid particular attention to differences in ethnicity, language, and culture when they cared for South Asian women as well as other ethnic groups. Previous research recognizes the importance of respectful and culturally safe interactions between indigenous patients and health care providers (Browne, 1997; Kearns & Dyck, 1996; Ramsden, 1993). Despite these findings, health providers in this study appeared to treat cultural differences as problematic.

Findings from this study suggest there are various challenges to providing South Asian women with information about abnormal Pap test results. Language was an obvious barrier when predominantly English speaking health care providers cared for non-English speaking South Asian women. Most health care providers in this study presented non-English speaking women with written information and procedural instructions in English, without initially assessing the extent of their prior knowledge about Pap tests or previous health care experiences, or their
ability to understand and communicate in English. In order to further illuminate the notion of individuality and tailoring health care for women, some researchers have recognized that regardless of ethnicity, it is important to recognize that even though people from a country may share the same beliefs, values, and experiences, significant intra-ethnic diversity also exists (Hall, Stevens, & Meleis, 1994; Helman, 1994).

Most of the women and the health care providers at the colposcopy clinics reported that family physicians were not adequately informing the participants about the need for a Pap smears or test results. Furthermore, findings indicated that some South Asian physicians who could have communicated with South Asian women by providing language-specific information, neglected to do so. Previous research has demonstrated that although health professionals and patients sometimes shared similar ethnic backgrounds, differences in beliefs and values, gender, class, education, and occupation created barriers to communication that outweighed shared cultural origins (Kleinman, 1988; Waxler-Morison, Anderson, & Richardson, 1990). Others have also observed that opposite-gendered interactions can be problematic for South Asian women and health care providers especially when issues related to gynecological concerns need to be addressed (Lynam, Gurm, & Dhari, 2000; Bottorff, Balneaves, Sent, Grewal, & Browne, 2001).

In this study, however, findings suggest that these problems can also occur when physicians are female and South Asian. Data suggested that some female South Asian family physicians referred women to English speaking gynecologists without providing more explicit information in relation to reasons for further evaluations. Furthermore, health care providers’ assumptions that most South Asian women are more compliant in comparison to other women and do not openly communicate with physicians because they are not interested, appeared to limit health care interactions in important ways. Such cultural stereotypes of South Asian women limit health care providers’ ability to provide individualized care.
The need for clarity and precision in informing women about their Pap smear results has been demonstrated through previous research (Marteau, Senior, & Sasieni, 2001). When language barriers exist, this becomes increasingly difficult. Although addressing language barriers is an essential component of health care, focusing on problems of communication as the primary source of difficulties for South Asian (and other) patients can divert attention away from the complex range of other impediments to health care (Browne, Johnson, Bottorff, Grewal, & Hilton, in press).

While most of the women and the health care providers believed that communication barriers were created by language and culture differences, a few young women who spoke English and had university or college level education had positive experiences with their physicians during their abnormal Pap test experience. Descriptions of the women’s and health care providers’ experiences illustrated that use of lay language, taking time to explain procedures and results during office consultations, and providing language-specific materials enhanced understanding for some participants. Other studies with ethnic groups also demonstrated that it is possible to communicate with women in different ways regardless of their ability to speak in English or not in order to meet their needs (Hunt et. al., 1998; Fitch et. al., 1998). Most of the health care providers and participants recognized the challenges that present themselves when English speaking male health care physicians provided care for non-English speaking South Asian women.

**Challenges in the Clinical Setting**

There were important differences in womens’ experiences during clinical visits for follow-up colposcopy examinations in the two clinical settings that were used for data collection. The two clinics used different approaches to health care delivery. The women-centered clinic, based out of a large hospital provided various gynecological procedures including Pap testing, colposcopy, and other examinations for women. However, the other colposcopy clinic, situated
in an ambulatory day care unit, shared space with other health services offered to male and female clients who came for various other procedures including minor day surgeries. In comparison, most of the participants’ descriptions of their experiences at the women-centered clinic were of comfort, ease, and respect, whereas the majority of women who visited the other clinic felt that decisions were pre-determined and patients were expected to follow through with the procedures at the health care providers’ pace, rather than be treated respectfully by allowing ample time for examinations. Findings from other studies have recognized the emphasis that participants placed on the amount of time health care providers spent with them along with the importance of respectful care (Browne, 1997; Kearns & Dyck, 1996). Furthermore, some of the participants at the ambulatory day care clinic shared that care could have been made more personal and respectful by attending to small details such as the provision of a drape to cover patients while being examined and a waiting area which provided some privacy.

Results show that participants from the women-centered clinic had more positive experiences in comparison to those from the other colposcopy clinic. Stemming from the principles of respect and autonomy, the women who visited the women-centered clinic, were given a choice regarding draping during an examination, and provided the opportunity to view a video presentation of the procedure in the privacy of a room. Participants felt that small details such as respecting women’s privacy and modesty demonstrated respectful care. Previous research with other ethnic populations has shown that demonstrations of respectful care, including the emphasis on trusting relationships and flexible individualized approaches to meet diverse individual needs, is key during health care interactions (Browne, & Fiske, 2001; Kirkham, 1998).

Time pressures and the need for efficiency shaped the ways health care services were provided. These factors were vividly reflected in the experiences of women in this study. The women thought their doctors did not have time to give full explanations so they hesitated to ask
questions in clinics. They felt like they were treated like robots, rather than as persons. A few participants thought that better eye contact from the physician whilst discussing the results would have humanized the clinic procedures for them. This would have made a tremendous difference in being treated respectfully. Women recognized that time constraints were due to busy clinic schedules, but believed that just a few minutes of the physician’s time spent discussing an individual’s health care was not too much to ask for. Other studies have suggested that nurses working in collaboration with physicians could provide supportive care during screening without the time constraints experienced by most physicians (Kotke & Trapp, 1998; Neale, 1999).

Most of the health care providers were quick to point out the need for professional interpreters because of language barriers. They agreed that interpreter services are an integral part to the provision of basic and effective health care for those who face language barriers in seeking and using health services. Further, they concurred that effective communication between the patient and the health care provider is needed for accurate diagnosis and timely treatment (Haffner, 1992; Maltby, 1999; Tang 1999). Despite these recommendations, interpreters were not always provided. The lack of attention to language services limited women’s ability to be involved in health care decisions and, in turn, inadvertently served to maintain stereotypes of women as uninterested, uninformed, and uneducated (Anderson, 2000; Hall et. al., 1994; Sherwin, 1992). Simply ensuring the availability of professional interpreters or language-specific written materials may not entirely address these issues. Anderson and Kirkham (1998) argue that often times when women are able to attend a clinic, and find someone to interpret for them, they may not receive the help they need. This occurs because women’s frameworks of meaning and interpretation may differ significantly from those of the health professionals whose explanatory frameworks are steeped in the culture of Western biomedicine. Understanding the ways in which culture can shape people’s responses to health and illness can help health care providers to adapt their practices to be more responsive to specific groups (Browne et. al., 2001). Other studies
recognized that while providing language-appropriate services is important, other factors including the combined effects of ethnicity, gender, social class, women’s beliefs and values related to Pap testing, and the influence of other health and social concerns influence women’s health care experiences (Bottorff, Balneaves, Sent, Grewal, & Browne, 2001; Fitch et. al., 1998).

Implications For Nursing Practice

Findings from this study reveal that strategies should be targeted toward clearer communication with South Asian women, along with individualized care which in turn, would enhance understanding of the cervical screening program and the follow-up diagnostic care. These strategies confront existing health policies around interpretive services and language-specific written materials for ethnic groups. Recommendations include providing interpreters to form part of the staff at the colposcopy clinic, thus ensuring the availability of professional interpretive services. In institutions that serves a large South Asian population interpreters could function as cultural mediators and advocates for South Asian women. Providing language-specific reading material at the source of the initial screening and the receipt of the abnormal result will ensure that women are aware of procedures for the follow-up examinations at the colposcopy clinic. With increasing knowledge, the expected clinic visits are likely to be less stressful for women and they will be more likely to participate in re-screening.

The findings in this study provide evidence regarding important principles around developing women-centered clinics and recognize the challenges of implementing such programs. Based on the success of the afore-mentioned women-centered clinic in this study, comprehensive policies that support women’s health care centers, both existing and new, need to be examined. Evidence from other studies support the need for women-centered care when providing Pap testing. However, the development of services that fully embody the components of women-centered care may sometimes be hampered by structures in the health care system (Bottorff et. al., 2001; Fitch et. al., 1998). Since the findings illustrate difficulties that some
women had communicating with male health care providers, it may be necessary to educate more female nurses to perform Pap tests and colposcopy examinations.

Offering information on Pap testing and follow-up procedures in a variety of formats (e.g. written, verbal, video) is important. This will help to ensure that women with different learning preferences will have access to the information they need. Physicians and nurses should take responsibility for informing women about the benefits of regular Pap test screening and the importance of complying with follow-up recommendations. Staff at colposcopy clinics should not assume that family physicians have provided information about the follow-up procedure while delivering abnormal Pap test results.

**Implications For Nursing Education**

This study supports nursing curricula that expose nursing students at the most basic level of their education to ‘patient teaching and learning’ courses, and cultural assessment skills. Education strategies that teach students to be careful in making assumptions about an individual’s beliefs and values, to give clients information about procedures and to involve patients in decision-making are important. The Registered Nurses Association of British Columbia (1999) monitor nursing school curricula to ensure strategic courses in ethics, socio-cultural constructions of health and illness, and patient teaching and learning are included to prepare nurses for their initial entry into the workforce.

Although studies reveal an increasing recognition of the need to understand cultural influences on the construction of health meanings and health practices, this information may not be available to practicing nurses. Thus, providing continuing education on these topics is vitally important (Lynam & Young, 2000; Anderson, 1998).

Critical self-awareness of the nurse’s own culture and recognition of his/her biases is something that can be learned and fostered to counter stereotyping (Reimer-Kirkham, 2000). Providing culturally safe care prompts us to question our assumptions about South Asian women,
to locate women’s health concerns within a structural context and to connect the dynamics of individual encounters to broader social issues (Browne & Fiske, 2001). Furthermore, this line of questioning differs significantly from culturalist approaches that focus (superficially) on cultural sensitivity or basic communication strategies. Therefore, cultural safety as an analytic lens can help to counter these tendencies by encouraging researchers, practitioners, and educators to interrogate this simplistic assumption. It is feasible and desirable that nurses ‘begin’ practice with the knowledge, skills and conceptual orientation that practice demands. The complexity of providing care for culturally diverse clients can be addressed by providing appropriate formal and informal education programs for nursing students and practicing nurses to help prepare skilled facilitators who are able to create safe environments in which frank, but respectful discussions can take place (Reimer-Kirkham, 2000).

**Implications for Nursing Research**

This study represents a preliminary understanding of South Asian women’s experiences with the receipt of an abnormal Pap test result, within the routines of mainstream healthcare delivery. In the present discourse of multiculturism, ethnicity, visible minority status, and the like, inherent social relations mask the processes that determine people’s experiences, and create stereotypes; therefore, extending into what is assumed to be people’s beliefs and practices concerning health and illness (Anderson & Kirkham, 1998). Findings in this study reveal similar inherent stereotypes that were frequently created by health care providers about South Asian women’s beliefs and values in relation to health care.

Future qualitative studies might incorporate English-speaking women, as well as non-English speaking women from one minority group in order to explore how experiences of abnormal Pap tests differ in relation to women’s fluency in English. The findings in this study, also suggested that language is not the only barrier when communicating with South Asian women. A future program of research attempting to identify the complexities between social
class, culture, and nurse-patient and physician-patient relationships would help uncover how gender and language intersect with societal class and institutional levels when South Asian women interact with health care providers.

Further qualitative research describing how language is used when health care providers are discussing health issues or informing patients of the diagnosis of cancer would extend existing knowledge of how contextual factors including culture, societal values, the setting of the health care, and the institutional climate increase or decrease understanding and de-mystify cervical cancer. Other studies exploring the adequacy and level of information that physicians’ secretaries provide for women in relation to Pap test results, will further enhance an understanding of the physicians’ secretary’s role in the health care system.

Summary and Conclusion

This chapter has presented a discussion of the more significant findings of this study and their implications for practice, education, and research. In conclusion, this study has explored South Asian women’s experiences with the receipt of their abnormal Pap test results and has presented their voices along with the experiences of the health care providers caring for South Asian women. The findings illuminate the various co-existing complexities of both women as well as health care providers in relation to the mainstream health care system in Canada. The study, thus, provides some direction for promoting culturally sensitive care and offers a vision for practicing within the provisions that are marked by respect and beyond simple definitions of culture and ethnicity (Reimer-Kirkham, 2000).
REFERENCES


Appendix A

LETTERS OF INVITATION (WOMEN)

Study Title: South Asian Women's Experiences Associated with Receiving Abnormal Pap Test Results.

Investigators: Dr. Joan Bottorff, Professor (Nursing) Phone: XXX-XXXX
   University of British Columbia

   Savitri Singh, Master's Nursing student Phone: XXX-XXXX
   University of British Columbia

Contact Person: Savitri Singh, Master's Nursing student, UBC. Phone: XXX-XXXX

Researchers from the School of Nursing at the University of British Columbia would like to inform you about a study they are conducting with South Asian women who have received the results of an atypical (abnormal) Pap test and invite you to consider participating in this study.

Purpose:
The purpose of this study is to understand South Asian women's experiences when they receive the results of an atypical Pap test and follow-up diagnostic examinations. The researchers are interested in knowing about your experiences of receiving the results of your Pap test and recommended follow-up examinations. With this information, they hope to be able to provide better care for women in this situation.

Procedure:
Participation in this study involves an interview about your experiences related to receiving the results of your Pap test and recommended follow-up examinations. This interview will last approximately 30-40 minutes at a location of your choice. The interview will be audiotaped by the interviewer.

Savitri Singh will be calling you after you have received this letter to answer any questions that you may have regarding this study. If after receiving this letter, you feel that you are eligible to be included in this study and you would like to participate, feel free to give Savitri Singh a call at the number listed above. The information you provide will remain confidential and your name will not be used in any part of the study. You may refuse to participate in the study or withdraw from the study at any time, and such actions will in no way affect the health care you receive.

If you have any questions or concerns after receiving this letter, please feel free to give the researchers a call at the numbers listed above. Thank you for considering participation in this study.

Yours sincerely,
Andrea Bisaillon, Patient Services Manager,
Women’s Clinic, CP E7, VHHSC
Study Title: South Asian Women's Experiences Associated with Receiving Abnormal Pap Test Results.

Investigators: Dr. Joan Bottorff, Professor (Nursing) University of British Columbia
Savitri Singh, Master's Nursing student University of British Columbia

Contact Person: Savitri Singh, Master's Nursing student, UBC. Phone: XXX-XXXX

Researchers from the School of Nursing at the University of British Columbia would like to inform you about a study they are conducting with South Asian women who have received the results of an atypical (abnormal) Pap test and invite you to consider participating in this study.

Purpose:
The purpose of this study is to understand South Asian women's experiences when they receive the results of an atypical Pap test and follow-up diagnostic examinations. The researchers are interested in knowing about your experiences of receiving the results of your Pap test and recommended follow-up examinations. With this information, they hope to be able to provide better care for women in this situation.

Procedure:
Participation in this study involves an interview about your experiences related to receiving the results of your Pap test and recommended follow-up examinations. This interview will last approximately 30-40 minutes at a location of your choice. The interview will be audiotaped by the interviewer.

Savitri Singh will be calling you after you have received this letter to answer any questions that you may have regarding this study. If after receiving this letter, you feel that you are eligible to be included in this study and you would like to participate, feel free to give Savitri Singh a call at the number listed above. The information you provide will remain confidential, and your name will not be used in any part of the study. You may refuse to participate in the study or withdraw from the study at any time, and such actions will in no way affect the health care you receive.

If you have any questions or concerns after receiving this letter, please feel free to give the researchers a call at the numbers listed above. Thank you for considering participation in this study.

Yours sincerely,
June Harrison, Unit Manager,
Ambulatory Day Care Clinic
Surrey Memorial Hospital
Appendix B
LETTER OF INVITATION (HEALTH CARE PROVIDERS)

Study Title: South Asian Women's Experiences Associated with Receiving Abnormal Pap Test Results.

Investigators: Dr. Joan Bottorff, Professor (Nursing) Phone: XXX-XXXX
University of British Columbia

Savitri Singh, Master's Nursing student Phone: XXX-XXXX
University of British Columbia

Contact Person: Savitri Singh, Master's Nursing student, UBC. Phone: XXX-XXXX

Researchers from the School of Nursing at the University of British Columbia would like to inform you about a study they are conducting regarding South Asian women's experiences related to receiving the results of an atypical (abnormal) Pap test and invite you to consider participating in this study.

Purpose:
The purpose of this study is to understand South Asian women's experiences when they receive the results of an abnormal Pap test and follow-up diagnostic examinations. The researchers are interested in knowing about your experiences of working with South Asian women who have received the results of a Pap test and recommended follow-up diagnostic examinations. With this information, we hope to be able to provide better care for women in this situation.

Procedure:
Participation in this study involves an interview about your experiences related to working with South Asian women who have received the results of an abnormal Pap test result and recommended follow-up examinations. This interview will last approximately 15 minutes at a location of your choice. The interview will be audio-taped by the interviewer.

Savitri Singh will be calling you after you have received this letter to answer any questions that you may have regarding this study. If after receiving this letter, you feel that you are eligible to be included in this study and you would like to participate, feel free to give Savitri Singh a call at the number listed above. The information you provide will remain confidential, and your name will not be used in any part of the study. You may refuse to participate in the study or withdraw from the study at any time.

If you have any questions or concerns after receiving this letter, please feel free to give us a call at the numbers listed above. Thank you for considering to participate in our study.

Yours sincerely,
Joan L. Bottorff, PhD, RN
Professor, School of Nursing, UBC
Appendix C
PATIENT INFORMED CONSENT
(UBC Letterhead)

Study Title: South Asian Women's Experiences Associated with Receiving Abnormal Pap Test Results

Investigator: Dr. Joan Bottorff, Professor (Nursing) Phone: XXX-XXXX
University of British Columbia

Savitri Singh, BScN, Master’s Nursing student Phone: XXX-XXXX
University of British Columbia

Contact Person: Savitri Singh, Master's Nursing student, UBC. Phone: XXX-XXXX

Purpose:

The purpose of this study is to understand South Asian women's experiences when they receive the results of an atypical (abnormal) Pap test and recommended follow-up diagnostic examinations. With this information, we hope to be able to provide better care for women in this situation.

Study Procedures:

You will be interviewed about your experiences of receiving the results of an atypical (abnormal) Pap test and your recommended follow-up diagnostic examinations. This interview will last approximately 30-40 minutes at a location of your choice. The interview will be audi-taped, and then typed out by a secretary. Some informants may be asked to participate in a second interview to review and comment on preliminary findings.

Risks:

There are no experimental procedures being administered in this study. There are no expected risks to the participants from this study.

Potential Benefits:

You will not receive any direct benefits from participating in this study. However, it is anticipated that the results of this research may provide information that will help develop better care services for South Asian who receive results of an atypical (abnormal) Pap test and follow-up diagnostic examinations.
Confidentiality:

Any information resulting from this research study will be kept strictly confidential. The notes, the audio tapes, and the interview transcripts will have all identifying information removed and your name will not be used in the research reports. Number codes will be used to identify participants in this study. Information obtained in this study may also be used for educational purposes and research that involves a secondary analysis of the observations and interviews, with the understanding that any additional research projects that use the interviews will be approved by the appropriate university committees.

If you have any questions or desire further information about this study, you may contact Dr. Joan Bottorff or Savitri Singh at the numbers listed above. If you have any concerns about your rights as a research subject, you may contact the director of Research Services at the University of British Columbia, Dr. Richard Spratley, at 822-8598.

Consent:

I understand that my taking part in this research project is voluntary and up to me. My decision to take part or not to take part will in no way influence my continuing health care. If I decide to take part and then change my mind, I am free to withdraw from the project at anytime.

I have received a copy of the consent form for my records and I consent to participate in this study.

_________________________    _________________
Subject signature                 Date

_________________________    _________________
Signature of a Witness            Date

* Consent form for client will be translated into Punjabi
Appendix D

HEALTH CARE PROVIDERS INFORMED CONSENT

(UBC Letterhead)

Title: South Asian Women's Experiences Associated with Receiving Abnormal Pap Test Results.

Investigator: Dr. Joan Bottorff, Professor (Nursing) Phone: XXX-XXXX
University of British Columbia

Savithri Singh, BScN, and Master's Nursing student Phone: XXX-XXXX
University of British Columbia

Contact Person: Savithri Singh, Master's Nursing student, UBC. Phone: XXX-XXXX

Purpose:

The purpose of this study is to understand South Asian women's experiences when they receive the results of an abnormal Pap test and recommended follow-up diagnostic examinations. With this information, we hope to be able to provide better care for women in this situation.

Procedures:

A short interview focusing on your experiences of working with South Asian women who have received with an abnormal Pap test and recommended follow-up diagnostic examinations will be done. This interview will last approximately 15 minutes and will be done at your convenience. The interview will be audio-taped by the interviewer and later transcribed and typed by a secretary.

Risks:

There are no anticipated risks related to participation in this study.

Potential Benefits:

You will not receive any direct benefits from participating in this study. However, it is anticipated that the results of this research may provide information that will help develop better care services for South Asian who receive results of an abnormal Pap test and recommended follow-up examinations.
Confidentiality:

Any information resulting from this research study will be kept strictly confidential. The notes, the audio tapes, and the interview transcripts will have all identifying information removed and your name will not be used in the research reports. Number codes will be used to identify participants in this study. Information obtained in this study may also be used for educational purposes and research that involves a secondary analysis of the interviews, with the understanding that any additional research projects that use the interviews will be approved by the appropriate university committees.

If you have any questions or desire further information about this study, you may contact Dr. Joan Bottorff or Savitri Singh at the numbers listed above. If you have any concerns about your rights as a research subject, you may contact the director of Research Services at the University of British Columbia, Dr. Richard Spratley, at 822-8598.

Consent:

I understand that my taking part in this research project is voluntary and up to me. If I decide to take part and then change my mind, I am free to withdraw from the project at anytime.

I have received a copy of the consent form for my records and I consent to participate in this study.

Subject signature ___________________________ Date __________

______________________________________________
Signature of a Witness __________________ Date __________
Appendix E

Study Title: South Asian Women’s Experiences Associated with Receiving Abnormal Pap Test Results

Interview guide for women

1. I am interested in learning about how you first learned about your Pap test results. Can you tell me how this happened and what you learned?

2. What were your reactions to this news? Can you tell me how you felt and who you shared this with?

3. Most women who receive this kind of test results you did have other tests. Can you tell me more about these and what they were like for you?

4. Not all women have the same kind of experience when they find out about the results of their first Pap test. Can you tell me more about your experiences after you found out about the result?

5. I wanted to know if you could share your experience at the colposcopy clinic with us. What was it like for you while you were at the clinic? What was most difficult? What was most helpful?

6. How have your experiences changed the way you plan to take care of your health? Your plans for future Pap tests?

7. Do you have any advice about what should be done to improve services for women who receive atypical Pap test results?

8. What would you tell another woman who just received this kind of result? What advice would you have for her, based on your experience?
Appendix F

Study Title: South Asian Women's Experiences Associated with Receiving Abnormal Pap Test Results

Interview guide for health care providers working in colposcopy clinics

1. I understand that South Asian women come for treatment at this colposcopy clinic. I would like you to tell me about your experiences in working with South Asian women at the clinic. How do South Asian women appear to respond to receiving an abnormal Pap test result? How does this influence their experiences at the colposcopy clinic?

2. In your experiences working with women, what kind of questions or information do these women seek while visiting the clinic? In your experience, is there a difference or similarity in the kinds of questions or information that South Asian women ask in comparison to other women? How do you attempt to meet their information needs?

3. What are your experiences working with other ethnocultural populations? In your experience, what do you see as differences or as similarities when comparing South Asian women with women from other populations?

4. Some South Asian women have language barriers, which may pose a problem for both the health care worker and women. Could you elaborate on the strategies that you use to overcome these difficulties? How are you able to explain clinic procedures to them?

5. What do you think is the biggest challenge in providing services to South Asian women?

6. Based on your experiences, what recommendations do you have for improving services to South Asian women who receive abnormal Pap test results and follow-up diagnostic tests?
Appendix G

Study Title: South Asian Women's Experiences Associated with Received Abnormal Pap Test Results

Interview guide for family physicians

1. Are there unique challenges to caring/working with South Asian women who have received abnormal Pap test results? How do you inform South Asian women of abnormal test results and what do you usually tell them? How do women respond?

2. In your experiences working with women, what kind of questions regarding an abnormal Pap test result and follow-up diagnostic procedures, are the ones most women ask about? Is there a difference in the kinds of questions that South Asian women ask in comparison to other women? Who usually provides women with this information and how is this done?

3. In your experience, what are the biggest challenges in ensuring that women follow through with recommended follow-up diagnostic procedures after an abnormal Pap test result?

4. How does the experience of an abnormal Pap test influence women's subsequent screening practices?

5. Do you have any advise about how we can improve services for South Asian women who receive abnormal Pap test results?