TAKING CARE OF YOURSELF: A GROUNDED THEORY STUDY ABOUT HOW YOUNG WOMEN MAKE A DECISION ABOUT HAVING A PAPANICOLAU TEST

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YOUNG WOMEN MAKE A DECISION ABOUT HAVING A PAPANICOLAU TEST

by

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Abstract

Newfoundland has one of the highest rates of cervical cancer in Canada and the western region of Newfoundland has the lowest cervical cancer screening rates. Young women, in particular, have a potential risk for cervical cancer. They initiate sexual intercourse at an early age, have an increased risk for sexually transmitted diseases and may not have the knowledge to access cervical cancer screening tests. The effectiveness of the Papanicolau test in reducing morbidity and mortality from cervical cancer is well accepted. The purpose of this study was to use a grounded theory approach to identify and describe the social processes that influence young women in western Newfoundland to make a decision about having a Papanicolau test. Interviews were conducted with 14 women, ages 19-29. Three main categories emerged from the data to show how these young women made decisions about having a Papanicolau test. Acquiring significant information was the first category. Using the information characterized the second category and the third category of 'changing perceptions' showed how young women's decision to incorporate having a Pap test into their regular health routine was reached. The central category that explained the relationship among all the categories was 'taking care of yourself'.

The implications for nursing practice, nursing education and nursing research are included in the study findings.

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Chapter One

Introduction

Cervical cancer is the second leading cause of cancer death in women aged 25-39 (Franco, Franco-Duarte, & Ferenczy, 2001; Jennings-Dozier & Lawrence, 2000; Yoder & Rubin, 1992). In recent decades, mortality rates from cancer of the cervix have been decreasing in industrialized countries. While this trend has also been observed in Canada, it is still estimated that there will be 1400 new cases and 410 deaths from cancer of the cervix in this country in 2002 (National Cancer Institute of Canada, 2002). In Newfoundland, the cervical cancer rates are 30% - 40% higher than the rest of the country (Newfoundland Cancer Treatment and Research Foundation, 1997). Although the mortality rates from this cancer are decreasing, there has been an increase in the incidence of precancerous lesions in women less than 35 years of age (Antilla et al., 1999; Arraiz, Wigle, & Yang, 1990; Austoker, 1994; Liu, Semenciw, & Mao, 2001; Nold, 1998; Roye, 1993).

Cervical cancer is considered preventable because there is a long interval between the appearance of precancerous lesions and cervical cancer (Austoker, 1994; Grunfeld, 1997; Lee & Flynn, 2000). This interval provides an opportunity to detect and treat women with cervical lesions before the appearance of cervical cancer.

Problem Statement

The Papanicolaou (Pap) test is able to detect precancerous lesions and is

considered the most effective and economical test available for cervical cancer screening (Price, Easton, Telljohann, & Wallace, 1996). Regular cervical cancer screening reduces the incidence of disease and mortality from cervical cancer. In western Newfoundland, the rates of cervical cancer screening in young women, ages 19-29, remain low (Newfoundland Cancer Treatment and Research Foundation, 1997). This underutilization of an effective, safe screening tool indicates that young women are not making the decision to have a Pap test. This is a women's health issue that is a cause for concern and information is required about how young women make the decision to have a pap test.

The greatest risk factor for cervical cancer is never having a Pap test. However, researchers have identified other risk factors that increase a woman's susceptibility to this disease. The risk factors that place women at a higher risk for cervical cancer include sex partners who have multiple sex partners, early initiation of sexual intercourse, low socio-economic status, increasing age, and cigarette smoking (Aikins Murphy, 1995; Ibbotson, & Wyke, 1995; Langille, Beazley, Shoveller, & Johnston, 1994; Micheilutte et al., 1989; Price, Easton, Telljohann, & Wallace, 1996). Young women who have a combination of risk factors increase their potential for developing cervical cancer.

Women in Newfoundland have increased risk for cervical cancer and this risk can be related to a variety of factors. Adolescent girls are the only group among whom smoking initiation is increasing (Advisory Committee on Women's Health Surveillance,1999) and 60% of adolescent women in Newfoundland have had at least one

cigarette by the age 15 (West et al., 1996). Young women are having intercourse at an earlier age and as a result are more likely to have more than one partner. The Newfoundland and Labrador Student Drug Use Survey (1996) reported that 35.5% of students had intercourse in the 12 months prior to the survey and there had been an increase in the number of students who were sexually active from grades 7-9. More than one third of the students reported having had more than one partner in the twelve months preceding the survey.

Recent literature refers to the human papillomavirus (HPV), a sexually transmitted disease (STD), as a primary risk factor for certain types of cervical cancer (Foulks, 1998; Lovejoy, Roche, & McLean, 1997; Mays, Zimet, Winston, Kee, Dickes, & Su, 2000; Montero, Larkin, Houston, & Toney, 1997). Research shows that there is a high prevalence of HPV among adolescent and young women. (Austoker, 1994; Burak & Meyer, 1997; Ibbotson & Wyke 1995; Sellors et al., 2000). Many young females are engaging in behaviors associated with risk of STD's such as multiple partners, non-use or inconsistent use of condoms, and use of alcohol (Burst, 1998; Galambos & Tilton-Weaver, 1998; Guthrie et al., 1996). The Canadian STD Guidelines (Canadian Communicable Disease Report,1998) report that females ages 15-19 have the highest rate of chlamydia and gonorrhea infections in Canada. In Newfoundland the 0-19 year age group accounted for 14% of all reported cases of gonorrhea and 27% of all chlamydia cases in 1995 (West, Bavington, James, Ryan, & Longerich, 1996). HPV is not a reportable disease in Newfoundland so the prevalence of this STD in the province is not

known. It is evident that adolescents and young women are at risk of developing a STD, thus placing them at risk for developing HPV and precancerous lesions of the cervix or cervical cancer.

The western region of Newfoundland is a region of high unemployment, reaching 47% in some small communities (Statistics Canada, 1996). Education and income levels are low. These socio-economic factors also influence the health of young women in western Newfoundland and, when considered with the other cervical cancer risk factors, may increase their risk profile.

The purpose of this study was to determine how young women in western Newfoundland, between the ages 19-29, make decisions about having a Pap test.

Rationale

There is a growing body of research directed toward increasing the uptake of cervical cancer screening. Many studies have focused on the identification of barriers that would inhibit participation in cervical cancer screening (Fitch, Greenberg, Cava, Spaner, & Taylor, 1998; Neilson & Jones, 1998; Summers & Fullard, 1995). While there seems to be a great deal of information available about potential barriers to participation in cervical cancer screening, little is known about whether these barriers are similar for young women. In most studies, the experiences of young women are not considered separate from those of older women.

Research studies have also addressed the experiences of an underserved population, with consideration given to specific ethno-cultural groups (Bottorff,

Balneaves, Sent, Grewal, & Browne, 2001; Lee, 2000; Hiatt et al., 2001; Michielutte et al.,1989; Seow, Wong, Smith, & Lee, 1995). From the findings of these studies, the factors that influenced attendance for cervical cancer screening were the socio-economic status or culture of the women participating. As with other research studies, the experiences of young women were not considered separately from older women.

Lack of participation in cervical cancer screening has been recognized as a woman's health concern by many researchers. Research directed toward several different outreach strategies to recruit women to cervical cancer screening has been described in the literature and their effectiveness has been varied (Buehler & Parsons, 1997; Byles, Sanson-Fisher, Redmon, Dickinson, & Halpin, 1994; Forss et al., 2001). The wide range of ages in these studies limits the ability of health professionals to evaluate whether these strategies would be successful in recruiting young women for cervical cancer screening. If the factors that influence young women to have a Pap test are not identified in the research, then it is questionable whether strategies to increase attendance to cervical cancer screening would be effective in recruiting these young women for screening.

A number of theoretical models have been used to explain and predict cervical cancer screening behaviors (Hennig & Knowles, 1990; Jennings-Dozier, 1999; Murray & McMillan, 1993) and two were found that specifically considered young women (Burak & Meyer, 1997; McKinley & Billingham, 1998). These studies provided information about the health beliefs of young women, but did not consider the process of decision making or how young women were influenced to make a decision to have a Pap test.

While there is minimal understanding about how young women make health related decisions (Bravata, Rastegar, & Horwitz, 2002; Lewis, Corcoran-Perry, Narayan, & Lally, 1999), recent research has contributed to providing insights into the decision making process. Some studies have described the approaches to decision making in relation to illness and treatment options (Dempsey, Dracup & Moser, 1995; Lindberg & Nolan, 2001; Schaefer, Ladd, Gergits, & Gyauch, 2001). At least two studies have reported women's decision making regarding health screening behaviors (Forss et al., 2001; Lewis et al., 1999). However, none of these studies explored the process of decision making in young women.

In most of the studies, women are considered as a homogeneous group. There is little consideration given to the potential differences that may be influenced by age and experience. Despite the knowledge of barriers, risk factors, and potential interventions, there remains a paucity of research that describes how young women are influenced to have a Pap test. Therefore, current knowledge about young women's experiences, perceptions, and knowledge about Pap tests is inadequate to plan initiatives that would increase their attendance for cervical cancer screening.

Given the trends in cervical cancer screening rates, the potential risk for cervical cancer, and the limited research that considers the uniqueness of young women, it was timely to conduct a study that investigated how young women in western Newfoundland made a decision about having a Pap test. The knowledge gleaned from this study may be used to plan initiatives that will effectively increase cervical cancer screening rates in

young women. The findings from this study will contribute to the knowledge about cervical cancer screening, specifically about young women.

Research Question

This study was guided by the following research question: How do young women, between the ages of 19 and 29, make a decision about having a Pap test?

A review of the research literature related to cervical cancer screening is presented in Chapter Two.

Chapter Two

Literature Review

Young women are at increased risk for cervical cancer. They are initiating sexual intercourse at an early age, have an increased risk for sexually transmitted diseases and may not have the knowledge to access cervical cancer screening tests. The greatest risk for cervical cancer is never having a Pap test. The effectiveness of the Pap test in reducing morbidity and mortality from cervical cancer is well accepted. However, how young women make decisions about having a Pap test is not well identified in the literature.

The literature review in this chapter is organized according to the following topics: young women's understanding of cervical cancer screening, barriers to cervical cancer screening, and decision making.

Young Women's Understanding of Cervical Cancer Screening

Recent research studies have been conducted to identify young women's knowledge about cervical cancer and cervical cancer screening, their health beliefs and whether or not these young women would go for a Pap test (Burak & Meyer,1997; Kahn et al., 1999; McKinley & Billingham,1998). Kahn et al.(1999) conducted an exploratory study to assess adolescent girls' understanding of Pap tests and barriers to compliance with Pap test follow-up appointments. The study design incorporated four theories that have been useful in predicting cancer prevention behaviors: the health belief model, social cognitive theory, theory of planned behavior, and the transtheoretical model and stages of

change. Twenty-seven adolescent women, all of whom had been sexually active and had a Pap test, were recruited from an adolescent clinic or young parents' program in an urban area in the United States. Twelve young women participated in focus groups and fifteen women were individually interviewed. The interview guide was constructed from the focus group data and was structured to identify perceived health concerns, knowledge about Pap tests, and adolescent generated strategies to overcome barriers. The findings from this study are reported from the results of the individual interviews. The average age of the young women who were interviewed was 18.7 years. Although all 15 women identified prevention, early detection, and diagnosis of cancer as a benefit from having a Pap test, most did not understand the difference between a Pap test and a pelvic examination. This finding would suggest that understanding the mechanics of the procedure is not as critical for increasing attendance at cervical screening clinics as understanding the benefits of the procedure. Peers were identified as a main source of information and frequently the message these young women received was that a pelvic examination was painful. This study also reported that young women identified pain, embarrassment, fear of finding a problem and provider characteristics as potential barriers to participating in cervical cancer screening.

The research findings presented in this study contributed to the knowledge of how young women perceive cervical cancer screening and have implications for health care providers who are providing service to a population of young women. The importance of establishing trust, taking the time to explain the procedure and test results, ensuring

confidentiality, and a physician's ability to perform a gentle examination were considered favorable provider characteristics.

Burak and Meyer (1997) used the Health Belief Model (HBM) framework to examine the beliefs about gynecological screening and Pap tests, as well as the gynecological screening behaviours and intentions of four hundred college women, ages 18-23. A questionnaire developed by the researchers was assessed for validity by a panel of experts in female and adolescent health, field tested and then assessed for reliability by the test-retest method. The self administered questionnaires were distributed to women living in on-campus residences. The findings from this study indicated that the majority of participants did not believe themselves susceptible to sexually transmitted diseases (STD's) nor were they aware of the link between STD's, specifically HPV, and cervical cancer. While most of the women considered cervical cancer a serious disease, they were unsure of their risk for this disease. Despite the perceived lack of susceptibility for STD's and limited knowledge about the potential risk of developing cervical cancer, almost all of the young women indicated that regular Pap tests and gynecological examinations were important for their health. Young women lacked knowledge about cervical cancer and cervical cancer risk factors but this lack of knowledge did not influence their participation in regular cervical cancer screening. These findings have implications for health promotion and health education. Program development or health promotion activities will need to build on the belief that Pap tests are important and reinforce that cervical cancer is a serious illness that can be mitigated with regular cervical cancer screening.

Differences between those women who had a Pap test and those who had not had a Pap test were identified. Women who had not had a Pap test or pelvic examinations were more likely to perceive these examinations as embarrassing and painful than did women who had examinations. Burak and Meyer (1997) also considered cues to action, that is, those factors that serve to prompt health related behaviors. Many women indicated that their mothers had discussed gynecological examinations with them and some said that they had been taught about Pap tests in sexual health education classes. Women who had participated in screening were more likely to have received a cue to attend than those who had not had a Pap test.

This research was useful in identifying beliefs about Pap tests and gynecological examinations but was less useful in predicting intentions to have a gynecological examination or Pap test. Based on this work, the authors concluded that further research that can be applied to understanding women's behavior is needed.

McKinley and Billingham (1998) used a correlational design to examine the relationship of health beliefs about cervical cancer and STD's to female undergraduates attendance for pelvic examination. The researchers expected that the Health Belief Model (HBM) combined with sexual activity, sexual orientation, age, and physique anxiety would provide an effective model for predicting pelvic examinations. Students were recruited from psychology courses and those from the introductory level courses were given credit for their participation. Three questionnaires were used: a basic questionnaire, a Likert type questionnaire reflecting the constructs of the HBM and a Social Physique Anxiety Scale

(SPAS). The study sample consisted of 120 female students, ranging in age from 18 to 22 years, who were mostly European American. The participants completed the self administered questionnaire booklets in groups of 2-15. Correlations between the HBM and individual differences measures showed that sexually active women were more likely to intend to obtain a Pap test. The results also indicated that health beliefs are important predictors of pelvic examination intentions for these women, with barriers and susceptibility being the most important. The participants believed themselves to be more susceptible to cancer than STD's, even though the rate of STD's in sexually active young women is higher than the rates of cervical cancer. They also perceived STD's to be more serious than cancer, that they could control their susceptibility to STD's but not to cancer, and that cervical cancer could be treated. The findings showed that there are links between women's intentions to obtain a pelvic examination, health beliefs, and sexual activity. These results are different from Burak and Meyer (1997) who found that health beliefs did not predict behavior; however, their study did not consider sexual activity in their examination of health beliefs. Young women who are sexually active are more likely to have had a Pap test. While Burak and Meyer's study showed the young women lack knowledge about STD's and their link to cervical cancer, McKinley and Billingham's study showed the lack of understanding about the seriousness of cervical cancer. Therefore, it is fair to conclude that there is a gap in some young women's knowledge young about cervical cancer.

Hasenyager (1999), a physician at a large university health centre, conducted a

survey questionnaire to assess knowledge of cervical disease and Pap smear screening. The questionnaire was completed by 154 college women when they attended a health centre for their yearly gynecological examination. The 43 item self-administered questionnaire was developed by the author and reviewed by clinicians and health educators for content and readability. Reliability was evaluated by the test-retest method of administering the questionnaire to a sub-sample of the population. The majority of the women who completed the questionnaire were attending the health centre to renew their prescription for oral contraceptives and were required to have a Pap test at that visit. The average age of the women who completed the questionnaire was 23.5 years; however, the range of ages was 18-57 years. Most of the women understood that a Pap test was a screening for precancerous and cancerous lesions of the cervix but few could identify the risk factors associated with cervical cancer. Approximately half of the women identified multiple sex partners, a history of sexually transmitted infections, and HPV as risk factors and fewer were aware of smoking, early intercourse, and Acquired Immune Deficiency Syndrome. These results are consistent with those of Burak and Meyer (1997) who also identified young women's lack knowledge about cervical cancer risk factors.

Hasenyager (1999) also reported that the women in this study identified lack of knowledge, pain, embarrassment, and the relationship with the service provider as possible barriers to having a Pap test. However, lack of knowledge and potential barriers to having a Pap test did not seem to affect the decision that these women made to have a Pap test. Their need for a prescription for birth control was the impetus for having a Pap test. The

main concern for the women in this study was the prevention of pregnancy.

The findings of fear and embarrassment are repeated in the research data with those women who do not have Pap tests. In her study on women's views about cervical screening, McKie (1993) found that beliefs and attitudes were the major deterrents to having a Pap test for women who had not had one. A multi-method research design was used for this study, incorporating both discussion groups and a questionnaire survey. The data obtained from a series of nine discussion groups formed the basis for the design of the questionnaire. The discussion group format ensured that the themes for the questionnaire and the language that would be used were reflective of the women living in the study area, which was two working class neighborhoods in the northeast of England.

The data for this study were collected from two age groups: 50-64 years and 20-34 years. A total of 302 women completed the questionnaire survey. The results reported in this study focussed on the 23% of women completing the questionnaire who had never had a Pap test. When these women were asked what would prompt them to go for a Pap test, the responses showed that the presence of symptoms was the strongest indicator to attendance for cervical screening. A small proportion of women indicated that they did not respond to a letter of invitation because they did not have any symptoms. This would suggest that women believed that health services are required only when they have a symptom that requires diagnosis or treatment. Other reasons given for non response to the letter of invitation included fear, embarrassment, and not wanting a test.

When these women were asked if they would consider going for a Pap test, more

than half responded in the negative. The responses of the non-attenders who would consider going for a Pap test were not analysed separately from those non-attenders who indicated that they would not go for a Pap test. It would be important to know the difference between these two groups, considering that there seems to be a group of women who could be influenced to change their health behavior and have a Pap test.

While the researchers recognized the need to examine the views of younger women, data from the two age groups were not analysed separately and a disproportionate number of women not having Pap tests were more than 50 years of age. The views of younger women are not represented and therefore, it is difficult to extract conclusions about a younger population of women.

The questionnaire used in McKie's study was designed to elicit individual responses and the researchers categorized these responses according to a preexisting set of categories. Beliefs and attitudes were considered major deterrents to having a Pap test. Further exploration of these beliefs and attitudes would have proved beneficial, considering that this was a population of women who did not have a Pap test and who are not always included in cervical screening research. The results helped to reinforce the need for health education and the belief that health promotion efforts should be directed toward changing attitudes and beliefs about cervical screening, especially the belief that a Pap test is unnecessary if a woman does not have "symptoms."

Summary. The study findings reported here demonstrated that young women lack knowledge of cervical cancer, cervical cancer risk factors and cervical cancer screening. A

limiting factor in these studies is that while they all identified that women lacked knowledge, they did not consider the same factors when assessing this knowledge, thereby making comparisons among the studies difficult. While Kahn et al.(1999) assessed knowledge of the Pap test procedure, others assessed screening behaviors and beliefs (Burak & Meyer, 1997; Hasenyager, 1999; McKinley & Billingham,1998). The research findings were also inconclusive on the factors that influenced attendance for a Pap test. Only one study (McKie, 1993) identified what women who had not had a pap test believed to be the strongest factor influencing their attendance for cervical cancer screening. Further research with a population of young women is required to understand the influence that knowledge of cervical cancer, cervical cancer risk factors, and cervical cancer screening would have on a young woman's decision to have a pap test.

Barriers to Cervical Cancer Screening

Despite the effectiveness and availability of the Pap test, not all young women are availing of the opportunity to participate in cervical cancer screening. By understanding the barriers to participation, health care providers may be able to develop interventions to minimize these barriers and influence young women to make a decision to have a pap test.

Eaker, Adami, and Sparen (2001) reported the results from a population base-case controlled study in Sweden. The aim of this study was to investigate whether attitudes and beliefs about cervical screening would affect a woman's choice to have a Pap test. Participants were randomly sampled from a population of women, aged 25-60 years, who did not have a history of in-situ or invasive cervical cancer. Information was collected

through telephone interviews with 430 women who were considered non-attenders, that is, had not had a Pap test in the last 3-5 years and 514 women who attended to cervical screening. The telephone interview consisted of questions constructed using the health belief model as a guide to assess the respondent's perceptions of risk, perceptions of benefits, and barriers to having a Pap test. Other questions were included about anxiety or worry about cancer, future intentions regarding cervical screening, and preference about receiving information. Most of the questions about attitude and beliefs were formulated as statements on a six point Likert scale.

Differences between those women who attended to cervical cancer screening and those who did not were identified. Women who were non-attenders did not perceive the benefits of having a Pap test nor did they perceive their risk of cervical cancer as severe. They identified time factors and economical factors as barriers to attending to cervical screening. The most common reasons for not having a Pap test were that the women believed the test was unnecessary because they felt healthy, they had reached menopause, or they did not require a prescription for oral contraceptives. Absence of symptoms and lack of understanding are consistent barriers identified in the literature. As well, women who did not attend for cervical screening preferred to receive written information about the Pap test, whereas those women who attended to cervical cancer screening preferred receiving information face to face. Women who attended to cervical screening had more anxiety about cancer and did not consider time or economical factors as barriers to having a Pap test. The differences between women who had a Pap test and those who did not

were accentuated as the length of time since last Pap test increased. Older women were less likely than younger women to participate in future screening. The age of older women was not indicated.

The results from this study are consistent with other studies that identify health beliefs and lack of knowledge as deterrents to attending to cervical screening and the perception that a Pap test is not necessary unless a woman is symptomatic (Arevian, Noureddine, & Kabakian, 1997; McKinley & Billingham, 1998; McKie, 1993; Summers & Fullard, 1995; White, 1995). The study sample is reflective of women living in an urban area of Sweden who had access to health services. The age range of participants is wide and it would be expected that women 25 years of age would have different attitudes and beliefs than women 65 years of age. These differences were not explored in this study.

Neilson and Jones (1998) found that fear, dislike of the test itself, and lack of knowledge were identified as reasons for non-attendance to cervical screening. The investigators completed a 34-item questionnaire using either face to face or telephone interviews. This questionnaire was adapted from a previously published questionnaire and was piloted with 10 women prior to completion. Data was collected from 72 women, ages 20-60 years, who had not had a Pap test. The majority of women who participated believed that cervical cancer could be treated successfully and more than half believed that all women should be screened, even though these women had not had a pap test. This study took place in Scotland and, as in most of the studies, the age range of the women participating was wide and the women are considered as a homogeneous group. The

sample size for this type of questionnaire survey design was small. Despite the limitations of this study, the findings support that women require more information about cervical cancer and cervical cancer screening. These findings are consistent with others that have identified lack of knowledge, pain, embarrassment, and the relationship with the service provider as possible barriers to having a Pap test (Burak & Meyer, 1997; Kahn et al., 1999; Murray & McMillan, 1993; Harokopos & Mcdermott, 1996; Hennig & Knowles, 1990).

Mays et al.(2000) used an exploratory descriptive design to examine women's knowledge and beliefs about genital warts, HPV, cervical cancer and Pap tests. A convenience sample of 20 adolescents from Indianapolis (14-18 years) and 20 adult women from Chicago (20-50 years) was recruited from waiting rooms at health clinics that provide service to a population of women with low socio-economic status. All of the women participated in semi-structured, face to face interviews which took approximately 30 minutes to complete. The interviews were audiotaped and then transcribed verbatim. Each participant was paid fifteen dollars. Questions for the interview guide were developed from an extensive literature review and addressed the major areas to be explored. While a high percentage from both age groups of women who were interviewed reported having had a Pap test, less than half could identify that the purpose of a Pap test is to identify precancerous or cancerous changes in the cervix. Of those that correctly identified the purpose of a Pap test, none mentioned the association of HPV and cervical cancer. Most of the women had no knowledge of the risk factors for cervical cancer and

knew little about HPV and the connection of HPV to genital warts, Pap tests, and cervical cancer. Although the sample size was small and the age range for the adult women was wide, the results from this study continue to reinforce that women lack knowledge about cervical cancer and STD's, and while not influencing their participation in cervical screening, this lack of knowledge could influence their decisions about other health protective behaviors, such as utilizing safer sexual practices. The findings from this study contribute to the understanding of women's knowledge and beliefs about HPV, cervical cancer, and cervical cancer screening. These findings also reinforce the need to discuss cervical cancer, HPV, and cervical cancer screening with sexually active women.

Summary. It is evident from the research that there is a void in the knowledge that women have about cervical cancer and cervical cancer screening. The research contributes to the understanding of potential barriers to cervical cancer screening. However, most of the studies represented women of varying ages making it difficult to assess the perceptions, knowledge, and experiences of young women. Further research is required to assess whether these barriers are similar for young women.

Decision Making

The process of decision making usually follows a sequence of activities and is influenced by culture, past experience, and an evaluation of the seriousness of the decision (Domar, 1986; Lindberg & Nolan, 2001; Monson, Jackson, & Livingston, 1996). The process that young women use to make health related decisions is not well defined in the literature although participation in preventive health care programs seems to be related to

people's underlying motivations and attitudes (McAllister & Farquar, 1992). What is known is that if women can "get the information . . . they could make very good decisions" (Pearson, 2001, p.334) and that it is important for women to feel empowered to take an active role in their health. One of the ways in which the women's health movement has worked to empower women is through the dissemination of health information (Women's Boston Health Book Collective, 1998).

Participation in health preventive behaviors and the factors that influence these behaviors has been examined in relation to specific behaviors, such as the initiation of sexual activity or seat belt usage (Monson, Jackson, & Livingston, 1996; Riccio-Howe, 1991) and mostly with an adolescent population. In recent research, health preventive behaviors in young adults have been explored, but there is limited research that addresses the participation of young women in health preventive behaviors.

In a longitudinal study in the United States to explore the role of parents and peers in influencing young people's health beliefs as they move from adolescence to adulthood, Lau, Quadrel and Hartman (1990) found that modeling of behavior was the most important socialization process by which parents and peers influence health behaviors. The researchers specifically explored health beliefs and behaviors concerning alcohol consumption, diet, exercise, and seat belt usage. Data were collected from a convenience sample of students who were entering a university. Baseline questionnaires were sent to all students accepted into a university during the summer prior to school beginning. Subsequent questionnaires were sent to those students who agreed to

participate at intervals during their first three years of university. A questionnaire was also sent to the parents of the students who agreed to participate in this study. The final sample consisted of parent-child pairs, both of whom had replied to the initial questionnaire. The final number of participating students at year three was 53. The ages of the participants were from 15-27 years, although most were between 17 and 19 years of age. The majority of participants in this study were white, from two parent families and from middle and upper class backgrounds thereby excluding those young people whose life influences and experiences may be very different.

The questionnaire in this study focused on six behaviors: eating habits, alcohol consumption, exercise, sleeping, smoking, and seat belt usage. All of these health behaviors addressed in this study are behaviors that are within people's control. They can make a decision to participate or not to participate in a specific health behavior.

The findings from this study suggested that parents and peers influence both health beliefs and health behavior. Parental influence was considered strong and lasted throughout the first year of university. The importance of parental consistency in teaching and demonstrating positive health practices was supported by the results of this study. The study identified that peers have more influence on university students during the second and third years of university. Lau, Quadrel and Hartman (1990) considered those factors that may influence whether a young person would participate in any of four behaviors. The factors that young people considered prior to making the choice to participate in a particular behavior were not considered. The process used to reach a decision to

participate in a particular behavior was not examined.

Lewis, Corcoran-Perry, Narayan, and Lally (1999) used a descriptive exploratory design to investigate how women approach making a decision about having a mammogram. All of the fifty women who participated in the study were white, 35 years or older and had made a decision about whether or not they would have a mammogram. The majority of women were recruited from a large metropolitan mammography clinic and semi-structured interviews, lasting 15-20 minutes, were conducted either face to face or via the telephone. The researchers indicated that the face to face and telephone interviews yielded comparable data. Interviews were audiotaped and transcribed. Content analysis was performed to identify the approaches women used to make decisions about mammography and three overall approaches to decision making emerged: thoughtful consideration, cursory consideration, and little or no consideration. The largest group of women (21) used a thoughtful consideration approach and considered factors such as age, risks and benefits of mammography. These women also considered personal experience and some practical considerations, such as time and transportation. The group with the least number (13) of women used little or no consideration in their approach to making a decision about mammography and for the most part relied on someone else to make the decision. These two approaches had clear characteristics and seemed to be easily identifiable. The middle group (16) of the women used a cursory approach and were more ambiguous in their decision making approach. It was not clear what factors these women considered as they made a decision. The fact that there were many women who did not

have a clear mechanism for making a decision is a cause for concern. Longer interviews may have given the researcher an opportunity to further explore the factors that these women bring to their decision making.

Mammography is a screening practice that is directed to older women or those with specific risk factors, unlike cervical cancer screening which is directed to a more inclusive group of women. This study provided some evidence of a decision making process for women considering a health screening activity and provided insight into the differing approaches that women bring to their decision making. However, comparisons to a group of young women are limited.

Forss et al.(2001) conducted an exploratory study with 63 women, aged 25-60 years, to investigate how healthy women in Sweden reason about their participation in an organized cervical screening program. Women were recruited from three health clinics as they waited to have a Pap test. Unstructured interviews, lasting 10-30 minutes, were initiated with questions designed to explore the variety of ways women reason about their attendance to cervical screening. These interviews were audiotaped and transcribed for the researchers to review. The authors used a "modified phenomenographic approach" to analyze the interview data. Analysis was completed with the research team reviewing and discussing each interview to reach a consensus about the categories. Four ways of reasoning about cervical screening attendance were identified.

The four ways of reasoning by women about attendance to cervical screening were described as follows:

a) focus on the test and the results. Women who focus on the test and the results are motivated to have a Pap test to detect early cervical changes.

b) focus on beneficial aspects of attendance, catalyzed by a letter of invitation. These women describe cervical screening positively and welcome the letter of invitation to remind them of the need for a Pap test.

c) focus on the letter of invitation, in overcoming hurdles to attendance. These women indicated that, while the letter served as a reminder, they perceived cervical screening as an unpleasant necessity.

d) focus on a proactive preventive role. These women were proactive in their own health promotion and cervical screening was only one facet of their health routine.

Interspersed throughout the four ways of reasoning were common themes that indicated that women had an understanding of cervical cancer and cervical cancer screening, as well as the importance of early detection of cancer. All of these women had a knowledge about cervical cancer and screening.

Forss et al. (2001) conducted this study in Sweden which has had an organized screening program since 1968. The younger women interviewed would have been exposed to the components of an organized screening program for a longer period of time, possibly receiving regular invitations to participate since 18 years of age. Their perceptions and knowledge about the importance of screening may have differed from that of older women. Even though a number of women were less than 29 years of age, the authors did not discriminate between age groups, so it is not known if the younger women reasoned in

similar ways or in four different ways. The perspective of women who attend to cervical screening is presented, which may explain the predominantly positive ways of reasoning that are described. Their decision to have a Pap test was influenced and reinforced by their participation in an organized screening program, regardless of their reason for attending. These women had a knowledge of cervical cancer and understood the importance of having a Pap test. This knowledge, their health beliefs, and the reminders from the program served to support their decision to have a Pap test.

The modified phenomenographic approach used in this study by Forss et al. (2001) is adapted from qualitative research methods. For a study of this design, a sample size of 63 women is large and the interviews are brief. This could be a limiting factor in the depth of the information acquired; however, the results do help to identify some of the potential influences on decision making.

Bush (2000) found that the messages within mass cervical screening programs influence a woman's decision to have a Pap test and that women have come to accept having a Pap test as part of a natural course of women's lives. Bush interviewed 35 women, 20-64 years of age, to explore personal interpretations of Pap tests and the ideas, language and concepts women use when talking about them. The women were purposively selected to reflect a broad range in terms of cervical screening experience, age, and socioeconomic criteria. The interviews lasted 30 minutes to two hours, were audiotaped and transcribed. Following transcription, the data were analyzed using a method of constant comparison. Bush found that women in the less than 30 age group

tended to talk about having a Pap test as an expected part of growing up, which was in contrast to the older women in the group who continued to feel somewhat uncomfortable with having an internal examination for preventive reasons. There was no other reference to age differences. Further references to the perceptions and feelings were discussed for all the women as a homogeneous group. The women described the feelings of normalcy and correctness associated with having a Pap test. Bush highlighted the way in which women were made to feel that having a Pap test was compulsory and that these feelings helped to frame women's perceptions of their bodies and their participation in a cervical screening program. The women described how the way cervical screening was presented influenced how they felt about their bodies and how they made decisions. This study provided insights into the way messages were perceived by the women who participated. These insights may suggest approaches that health care providers may consider to support women in their decision about having a Pap test. Similar to the previous study by Forss et al.(2001), this research presented cervical screening from the perspective of women who have Pap tests and who have participated in an organized screening program. These women may have been exposed to education and reminders for a longer period of time and, as a result, have incorporated having a Pap test into their health routine.

Summary. Research has identified some of the factors that influence the decision to participate in health preventive behaviors. The role of family values and peer influence was explored and their influence on some of the decisions young people make was described. However, little is known about the processes that these young people employ

prior to making a decision to participate in a particular behavior.

While research has provided some insights into the decision making process, the number of studies with a representation of young women is limited. The decision making process related to cervical cancer screening among young women has yet to be explored. Knowledge of those factors that influence decision making may provide the means to help young women to make a decision to have a pap test.

Conclusion

Research findings identified reasons for attending to cervical screening and the potential barriers to screening. The salient theme in these studies was the lack of knowledge related to cervical cancer and cervical cancer screening. This lack of knowledge was present regardless of socioeconomic status, culture, or education. However, young women, ages 19-29, were rarely considered as a separate cohort of women who participated in the research and there is limited research available about young women's perceptions, knowledge, and experiences of cervical cancer screening. Cultural attitudes and experiences can influence how women feel about their bodies and themselves (Anderson, 1997); therefore, it is reasonable to anticipate that young women's perceptions of cervical screening would be different from older women. The research does not provide an insight into how young women make a decision to have a Pap test.

The majority of studies were conducted outside of Canada with an urban population of women of varying ages. To date, it is not known how young women in Canada make a decision about having a Pap test. The purpose of the present study was to

explore how young women in western Newfoundland, between the ages 19-29, make decisions about having a Pap test. This study will add to the research about young women and cervical screening. Examining this topic from a qualitative perspective may provide nursing with information that may be used to design interventions to influence young women to have a Pap test.

The method and research design used to explore how young women make decisions about having a Pap test will be presented in the following chapter.

Chapter Three

Method

In this qualitative research study, a grounded theory approach, pioneered by Glaser and Strauss (1967), was used to explore young women's perceptions, experiences, and knowledge of cervical cancer screening and the influence that these have on how they make a decision about having a Pap test. Stern (1980) suggested that the grounded theory approach is appropriate to "investigate uncharted waters"(p. 20). This approach is useful when investigating areas of interest not previously explored or about which there is little information. It is apparent from the literature review in chapter two that there is a paucity of research which explores young women's decision making. I wanted to understand what factors would influence young women to make a decision to have a Pap test. Therefore, a grounded theory approach was appropriate for this research study.

In this chapter the grounded theory approach and its application in this study are described. Also, ethical considerations are presented.

Research Design

Grounded theory is a methodology for developing theory that is "discovered, developed, and provisionally verified through systematic data collection and analysis of the data pertaining to that phenomenon" (Strauss & Corbin, 1990, p.23). The approach used in this study was based on the method initially described by Glaser and Strauss (1967) and further explained by Strauss and Corbin (1998). Grounded theory has its roots in symbolic

interactionism. Blumer (1995) suggested that the term symbolic interaction refers to the "peculiar and distinctive character of interaction as it takes place between human beings"(p.206). People respond to events based on the meanings these events have for them, and these meanings are developed through experience or interactions that the individual has with others or with the environment. Symbolic interaction is an approach to studying human behavior and interaction that focuses on the meanings people give to events in their life (Wuest, 1995). The researcher examines the world from an individual's perspective and translates that perspective so that others can understand it.

In grounded theory, the researcher examines a phenomenon from the perspective of the people involved and looks for social processes that are imbedded in the activities that surround the topic of interest. The focus of the analysis is on behavior and the meaning participants give to the behavior. "The researcher needs to understand behavior as the participants understand it, learn about their world, learn their interpretation of self in the interaction, and share their definitions" (Chenitz & Swanson, 1986, p.7). The researcher becomes participant and observer of the subject's world. (Glaser & Strauss, 1967; Strauss & Corbin, 1998).

The key to grounded theory is that each piece of data is compared with every other piece of data and the researcher is coding, categorizing and conceptualizing almost from the onset of data collection (Strauss & Corbin, 1998). One of the fundamental characteristics of grounded theory is the constant comparative method of analysis. Constant comparative analysis refers to the continuous examination of data beginning with

comparing incident to incident and then grouping or classifying these incidents to develop categories. Categories are further compared to incidents and then categories are compared to categories. This is the process of taking the information from the data, conceptualizing the data, then integrating and reducing the data.

The method used to select the sample in grounded theory is theoretical sampling, a type of purposive sampling. Theoretical sampling is the process of data collection whereby the researcher jointly collects, codes, and analyses the data and decides what data to collect next (Glaser, 1979; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Theoretical sampling is done to discover categories and their properties. The sample size is determined by the data that are collected and the analysis of this data. Preliminary data collection is based on the participants' ability to describe aspects of the phenomena being studied. After preliminary data collection and analysis, the data collection becomes more focussed and data are collected according to the categories that arise from the analysis. Theoretical sampling continues until all categories are saturated. Saturation is achieved when no additional data are found and the researcher is confident that the categories are fully developed. The interviewing technique used in grounded theory is mainly unstructured interviewing to allow opportunities to fully explore the participants' experiences and thus the phenomena being studied.

In this study, the grounded theory approach ensured that the perspectives of young women were heard and reflected in the analysis as well as provided the researcher with an opportunity to gain insight into how some women made decisions about having a Pap test.

In the development of a grounded theory, the researcher must be cognizant of the end result of grounded theory and that is to inform social change (Keddy, Simms, & Stern, 1996).

Guba and Lincoln (1989) proposed four criteria for judging qualitative research: credibility, transferability, dependability, and confirmability. One measure of credibility is a clear articulation of the research method and, in the following sections, the application of the grounded theory method to this study is described.

Participants

The number of participants selected is a function of theoretical completeness. The selection of participants for this study continued until no new patterns or variations emerged from the interview data. The aim was to develop the categories and refine ideas (Charmaz, 2000). In this study, data saturation was reached after 14 interviews were completed and analysed.

The selection of study participants was purposive and included women, ages 19-29, residing in western Newfoundland. Young women within the selected age range consented to participate. To be eligible to participate in this study, young women had to meet the following criteria:

1. Must be mentally competent, able to read and speak English.

2. Must be between 19-29 years of age.

Fourteen women, aged 19-29, with a mean age of 25 years, were interviewed. Education levels ranged from completion of grade eight to completion of a graduate

degree. Employment status varied from student to seasonal employment to full time employment. The researcher did not ask questions about socio-economic status.

Procedure

Two methods of recruitment were used to identify potential participants for the study. An advertisement (see appendix A) was placed at post secondary institutions, community agencies, recreational facilities, grocery stores, and one fast food outlet asking that anyone interested in participating in the study contact the researcher. At the same time, the Assistant Chief Executive Officer of the Community Health Division of Health and Community Services Western was contacted and permission to contact public health nurses to solicit names of potential participants was requested (see appendix B). Approval was given (see appendix C) and public health nurses were contacted individually by telephone and given a copy of the advertisement. The nurses were asked if they would identify potential women, contact these women, and after briefly explaining the purpose of the study using the advertisement as a guide, ask the women if the researcher could contact them to provide further information. The public health nurses were advised to tell the women that agreeing to have the researcher contact them did not mean they were agreeing to participate in the study, but only agreeing to have the study further explained to them. While some of the young women were recruited with the assistance of public health nurses, most responded to the advertisement that was placed in the community.

The women who indicated a willingness to participate in the study were contacted by telephone by the researcher. During this initial, contact they were briefly informed of

the nature of the study and given an opportunity to ask questions about the study. If they continued to indicate that they were willing to participate in the study, an interview time was arranged. Six women, who were contacted by telephone, declined to participate once the study was explained to them. These women did not give a reason for declining to participate and none was requested. The women who did agree to continue were given a choice of time and place to be interviewed.

Setting

Ten of the women were interviewed in an office setting after work hours where the interviews were conducted in a private, quiet environment with little chance of interruption. Two interviews were conducted in the participant's home and two other interviews were conducted at the participant's place of work, in a quiet, private room. During all of the interviews privacy, quietness, and comfort were maintained. Although the women were interviewed in different settings, there were no differences noted in the responses.

Data Collection

Interview. Fourteen unstructured, in depth interviews were conducted to explore the perceptions of young women about having a Pap test. The data were collected from audiotaped interviews. Prior to beginning each interview, the tape recorder was tested to make sure it was functioning and that the audiotape was clear. At the beginning of the interview, permission to audiotape the interview was requested and the women were given a consent form to review and sign (see appendix D). The women were asked if they had

any questions, and time was allotted for general discussion before turning on the tape recorder. Demographic information was collected at this time and the interview was assigned a code number. This provided an opportunity for informal discussion and to set a relaxed tone for the interview. All the women were advised that the audiotapes would be transcribed and the tapes erased after the transcription. The women were assured of the confidentiality of information and of their right to withdraw from the study at any given time. Once the interview began, no one chose to withdraw and, while the researcher had anticipated that the topic could have been uncomfortable or elicit emotional responses, none of the women seemed uncomfortable with the discussion.

The interview began with a grand tour question (Spradley, 1979) which was, "Can you tell me about a time when you made a major decision in your life?" An interview guide was used to provide possible open-ended questions to direct the interview, if necessary (see Appendix E). Following these initial questions, the interview progressed in an open-ended manner as further questions were used to elicit the women's ideas, thoughts or experiences regarding their decision to have a Pap test. Probes, such as "yes" and "umm", were used to encourage participants to express more about their experiences and when further explanation was required. The researcher allowed for silences during the interview which enabled the women to gather their thoughts and consider the question. Water was provided during the interview. Initially, interviews were interactive, but as the study progressed, the questions became more focussed. The interview questions were directed to the themes emerging from the data, looking for similarities and differences to

fully develop the categories. The interviews lasted between 55-75 minutes and ended when the women indicated they had nothing more to add or that the questions were completely explored. The women were thanked for their participation and advised that a summary of the research data would be made available for them, if desired. As the data were coded and analyzed a decision was made about what data to collect at subsequent interviews. Interviewing was guided by the emerging data and continued until the researcher believed that the categories were fully developed and the interviews yielded no new information.

The numbered interviews were transcribed and kept separate from any identifying data. Both interviews and identifying data were kept in a locked filing cabinet when not being used and the researcher kept the key. No identifying data were entered in the computer or recorded on the audiotapes. In order to ensure anonymity, participants were advised that the interview would be coded and identifying data kept separate.

Data collection continued in this manner until no new information was obtained.

Data Analysis

Data analysis occurred simultaneously with data collection. Data collection and data analysis were not two discrete processes but occurred in alternating sequence (Glaser & Strauss, 1967; Strauss & Corbin, 1998). A total of fourteen hours of interview data were transcribed verbatim for analysis. The researcher listened to the audiotape to get an overall picture of the interview. Following transcription of the interview, the researcher listened to the audiotape with the transcribed interview a second time, comparing one to

the other to ensure that no words or sentences were missing. Once the audiotape and transcript were reviewed, the data were examined line by line and activities or ideas were given a name or label that represented them. Names or labels that were the participant's words are called in-vivo codes (Glaser & Strauss, 1967). These key words or in-vivo codes were underlined and written in the margin beside the indicators in the data. An example of an in-vivo code that described the perception of a Pap test was "that dreadful thing" and each interview was examined for this in-vivo code or the participant's perception of a Pap test. Each piece of data was coded with as many codes as possible and coding continued as the data were examined and compared for similarities and differences. This is called substantive or open coding (Corbin & Strauss,1998). To facilitate the process of substantive or open coding the researcher started completing contact summary sheets (Miles & Huberman, 1994). These were single sheets of paper upon which the researcher summarized key points from the data, wrote the list of codes and identified possible questions for future interviews. This activity was useful for memoing but became cumbersome for data management. The data became more manageable and meaningful when the researcher used the method of cutting up the interviews into "bibbitts" (Kirby & McKenna, 1989, p.135) and pasting these sections of data onto index cards. Each index card represented one code and was identified by interview number, page and line of the interview so that the section could easily be retrieved from the context of the whole interview. Codes were put into memos for subsequent interviews. Initially, many codes were identified. During this process, the researcher was in frequent contact with the thesis

supervisors to discuss these initial codes thereby creating a mechanism for credibility as codes were verified for further data collection.

Following coding of the first interview, the researcher completed a second interview. This second interview was coded and compared with the first interview. Each additional interview was analysed for similarities and differences and compared with the first interviews using the method of constant comparison. This technique allowed the researcher to find an active way to examine the data and to make the data meaningful (Janesick, 1994). As the interviews progressed, similarities and differences began to emerge from the data.

Axial coding is the process of reassembling data that were broken down during open coding (Strauss & Corbin,1998). During this second phase, data were coded, compared with other data and clustered together according to fit. Each cluster was analysed to conceptualize how they related to each other, and clusters that seemed to naturally relate to each other were given a label for a category. Categories represent phenomena. They describe what is going on and depict the "issues, concerns and matters that are important to those being studied" (Strauss & Corbin, 1998, p. 114.). For example, descriptors of the experience of having a Pap test were clustered together and then categorized as "being on the pill: the price you pay." At the completion of this process the categories were mutually exclusive. The researcher had a sense of completeness when all the clusters were categorized and no new categories emerged. The researcher moved back and forth between bits of data, moving index cards, and clustering codes. Memos were

reviewed and considered with the codes to make a decision about which data to collect to saturate the categories. The process was further aided by examining the data through the use of diagramming. This enabled the researcher to visualize the categories and consider how they may be linked together. At each step of the data analysis, the researcher was in contact with the thesis supervisors to discuss and verify the emerging categories. Although the steps in the research design are described sequentially, data collection and data analysis occurred simultaneously.

As each category was compared to every other category, the process of integrating and refining categories began. Four main categories emerged from the data: acquiring significant information, protecting yourself, changing perceptions, and taking care of yourself. They were compared to each other and the central category of "taking care of yourself" was identified. The central category that emerged was assessed to ensure it related to the other categories and could explain the variations, as well as the dominant theme from the data. The central category represents the main theme of the research and appears frequently in the data (Strauss & Corbin, 1998).

Selective sampling of the literature is suggested and can occur simultaneously with the analysis to further densify the categories and further reviewed for concepts that are related to the theory (Stern & Pyles, 1985). The process of refining the theory and ensuring that the categories are sufficiently developed is the last step in a grounded theory method. The literature review can fill in the gaps in the emerging theory and add completeness to the theoretical description. In this study, the literature was reviewed

initially to identify gaps in knowledge and to help provide rationale for the research. A second literature review was completed once the central category was identified.

Memos. Memos were notes kept by the researcher which showed the pathway of emerging theory. These were dated, titled, cross referenced and filed (Strauss & Corbin, 1998). This process began once coding was started. Memos were grounded in the data and included ideas about the relationships between codes and categories, as well as consideration for further data collection. These ideas were shared with the thesis advisors and served to initiate brainstorming sessions. These sessions assisted in focussing the analysis on the data and identifying categories. The notes were coded, categorized, and analysed in relation to the central theme.

Memoing provided the opportunity to reflect on the data and to plan for data collection and data analysis. The observations recorded during memoing can be clarified in the analysis. These memos are included in the analysis and further assist in providing data to verify or develop the theory.

Credibility and Auditability

Qualitative research requires commitment to the process of data collection and data analysis. Credibility is achieved when the process reflects grounded theory methodology. Credibility is one criterion used to ensure rigour in qualitative research. Measures to ensure the rigour of this study have been integrated into the design of this study. Grounded theory is a well structured methodology, appropriate for qualitative studies that want to look at social processes. This study was initiated with the support of

two faculty advisors knowledgeable in this method of inquiry and able to guide the student in the method. The number of women to be interviewed was not decided in advance, but interviewing continued until both the student and the advisors felt that sufficient data were obtained. The researcher further ensured auditability by maintaining a record of the process of data collection and analysis. Knowledge of the subject and continued interaction with the data provided the researcher with some sensitivity. In grounded theory, data items are checked against one another repeatedly and compared and contrasted frequently. By doing this, distortions, inaccuracies, and misinterpretations will gradually be discovered and resolved. The process is systematic and clearly delineated to serve as an audit trail so others can follow the research process and understand it. The audit trail and the frequent contacts with the thesis advisors to review, discuss and interpret the data reinforced the confirmability and dependability of the research findings (Guba & Lincoln, 1989). The data can be traced to their sources and should be evident to those who read the research study.

The process used in this grounded theory study ensured that truth and meaning were interpreted through the participant's point of view. Efforts were made to ensure that the data were a true reflection of the women's reality. The researcher, although a novice, followed the process described in grounded theory, consulted with experienced advisors regarding data collection and analysis and thus believes that the data collected were a reflection of the participants' reality.

Ethical Considerations

Approval to conduct this study was obtained from the Human Investigation Committee of Memorial University of Newfoundland (see appendix F) prior to beginning the study. Approval to contact public health nurses was obtained from the Assistant Chief Executive Officer of Community Health Division of the Health and Community Services agency.

The young women who participated in this study were given two copies of the written consent form to read and sign. Once signed, one of these copies was kept by the researcher and the other copy was given to the participant. The consent form was reviewed with each participant and the women were advised that their decision to participate was voluntary and that they could withdraw from the study at any time. The researcher's telephone number was made available to the women and they were encouraged to call if they had any questions or concerns following the interview. The women were advised that there were no anticipated health risks or benefits by being in this study. However, the information obtained from their interviews could benefit other women and provide health care providers with insights that may be used to improve practice.

Measures were taken to ensure confidentiality of all data at all times. All tapes and transcripts were coded and a master sheet with names and matched code numbers was kept in a locked filing cabinet to which only the researcher had the key. The transcripts were kept in a locked cabinet when not being used. The tapes were erased once they were

transcribed and reviewed for accuracy of transcription

The grounded theory methodology described in this chapter was used to explore how young women make a decision about having a Pap test. In the next chapter, the findings from this study are presented.

Chapter Four

Findings

The process of decision making depends on the nature of the particular task to be accomplished. Understanding the process of decision making may enable health care providers to assist women to make a decision about having a Pap test. In this study, unstructured, in depth interviews with 14 women in western Newfoundland were conducted to determine the process of how young women, between 19 and 29 years of age, make a decision about having a Pap test. In this chapter, the findings from the analysis of these interviews are reported.

Three main categories emerged from the data to show how these young women were influenced to make a decision about having a Pap test. The categories are as follows:

1. acquiring significant information
2. protecting yourself
3. changing perceptions

The central category that explains the relationship among all the categories is taking care of yourself (see Figure 4.1).

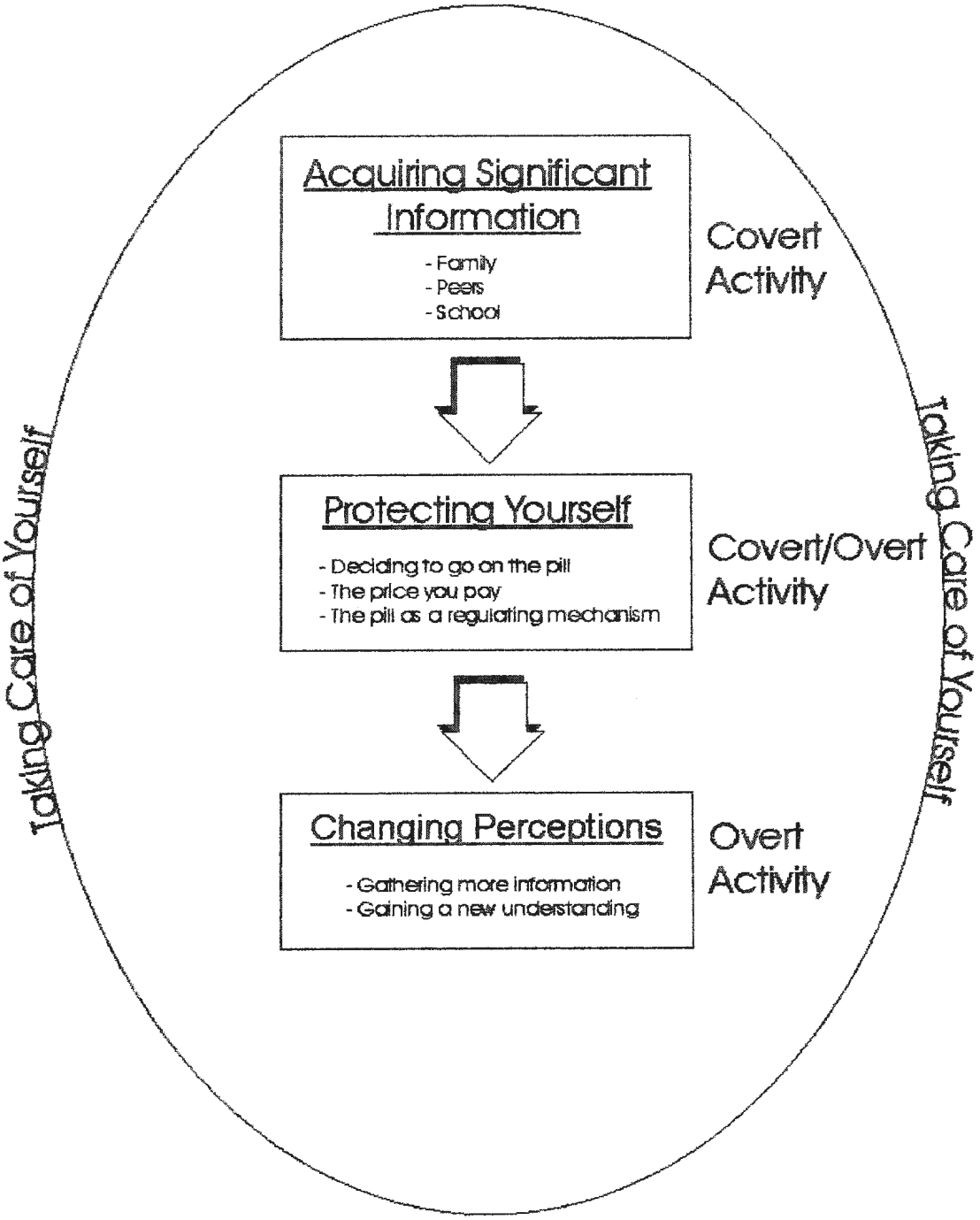

Figure 4.1: The Process of Taking Care of Yourself

Acquiring Significant Information

Young women in this study described how they learned, were encouraged, and were supported to make decisions about their personal health practices. The information they acquired from their family, peers, and school became significant when they used this information to make decisions that would affect their health. Initially, health beliefs and values were learned within a family environment through observation and discussions with their parents. For most of the participants, as they grew into young women, their circle of influence widened and they began to interact with other young women their age. They listened to peers and discussed issues significant in their lives at the time. Health education in the school exposed them to information which added to their repertoire of knowledge or served to reinforce some of the information they had acquired from family and peers. The young women in this study learned about health each time they were exposed to information from their family, friends, and school. These were influential sources of significant information, and they will be discussed to show how each played a role in providing these women with the information they needed to make decisions.

Family as a source of significant information. Knowledge about general health screening practices was acquired within a family environment as families communicated their health beliefs and values to their children. This information was communicated when parents made appointments for dental check-ups and vision screening for their children, thus establishing patterns of preventive health care. Information about healthy eating and daily hygiene was acquired as young women observed their family practising health

activities. The covert messages that these young women received from observing their family health practices were a significant source of information, and most of the women said it was within this family environment that they learned the importance of preventive health practices. One woman described the influence of family on healthy eating habits in the following way:

> ...and I, we always ate right. There was never a big lot of junk food in our house, and, you know, at recess we didn't take a bag of chips, we took an apple . . . I'd say we are pretty health conscious. And mom is pretty health conscious because of osteoporosis . . . she always stressed . . . drink your milk. Because of osteoporosis. You are younger this is the most important years of your life. Keep drinking and, you know, make sure you get your calcium intake.

Frequently, it was the mother in the family who arranged health care appointments, organized meals, and had a strong influence on the health practices of these young women. As one woman said:

> because mom, was always one who said go to the doctors and she has big faith in the doctors . . . then she goes to the doctor whenever something is wrong. She trusts them. She did instill that to us because she was always one if you are sick or whatever, go to the doctor and listen to what they say . . .

As these young women matured, they began to acquire significant information during their discussions with their mothers, aunts, or sisters. Many of the women in this study indicated that their mother was often one of the first sources of information about reproductive health. Frequently, the discussions about reproductive health began with information related to menstruation. Young women were beginning to ask questions and acquire information they could use to make health related decisions. As the women grew

older, family members supported and encouraged them to make their own health decisions. This provided an opportunity for many of the women to learn to make decisions. One of the young women described how her parents encouraged her to make decisions independently:

> My mom and dad are the type of people that tried to make me as independent as I could be . . . So I must say they were pretty lenient with my decisions . . . They helped us build our decision making skills I guess.

This overt support for learning how to make decisions was further shown when this woman described how she shared the decision to use birth control with her mother. She said:

> When I was seventeen . . . we sat down and talked about it . . . that I was going to go on birth control. We kind of talked about it together . . .

For many women, it was during these discussions about birth control with their mothers that they learned about having a Pap test. They also described examples of listening and absorbing information. They listened as their mothers described what they could expect to experience while having a Pap test:

> Yeah, my mom had encouraged me to go like when I was16 or 17, because she goes regularly, and she always encouraged me and I sort of held back from it. So she told me what it was going to be like.

Many of the women said their mothers went for regular Pap tests. When one woman was asked what prompted her to go for a Pap test, she responded, "My mom had her regular Pap smears and I guess, thinking, and I just started them and continue with regularly, yearly." Mothers did not have to say that a Pap test was important and this was evident

from the following comment: "I think my mom was my big role model for that because, you know, I knew that mom went regularly . . . I guess I followed in her foot steps." While the mother was a source of significant information for some women, others indicated that it was their sister who talked to them about birth control and having a Pap test. For some of the women, it was because of the relationship with their sisters that they also decided to incorporate the Pap test into their health activities.

Young women acquired significant information during family discussions related to beliefs about staying healthy and values, especially related to pregnancy. In the following quotation, one woman described the relationship with her mother and the link to family values when she talked about the decision to be sexually active.

> I think that part of it was probably how I was raised. I have a twin brother and they always sat down and talked to us about relationships. They would say I want you to be sure before you involve yourself in anything and Mom was always preaching to me about not getting pregnant young.

Not all information was overtly communicated as not all mothers were comfortable talking to their daughters about intimate topics. One woman described her attempt to talk about sexual intimacy with her mother and how her mother sent a clear message that she wanted to avoid the topic:

> I can't remember my mother explaining it to me. I remember once going to my mother in high school. I was thinking about going on the birth control pill cause I was going in a steady relationship and I said to her, and she ran away from me. I said to her, what do you think about this. And the next thing I knew she was walking on the top of the hill.

Through her mother's avoiding of the discussion, this daughter learned that this was not a

topic suitable for discussion. This young woman went on to elaborate about her family's position about unplanned pregnancy, which was "don't come home pregnant."

Many of the women said discussions with parents focussed on the prevention of pregnancy. Sexual intimacy was not discussed, but it was implied in statements that suggested that appropriate measures needed to be taken to prevent pregnancy. These discussions did not, however, include specifics about birth control measures. They reflected the family values related to young unmarried women being sexually intimate and having children.

Women acquired significant information from their family, either in the covert messages that were communicated through actions, avoidance of a topic, or in a direct overt communication. Clearly, messages were given to young women that facilitated their decision making related to reproductive health. The strongest message was, "don't come home pregnant"a message which communicated significant information about family values and health beliefs.

Other opportunities to acquire significant information occurred when women listened to their mothers having conversations with their friends. Through listening to her mother's conversations with friends one woman came to understand that Pap tests were important. She shared this memory with the following comment:

> Just you know hearing her views on it . . . Cause she would talk with her friend, other nurses and stuff, and they would talk about this sort of thing or whatever and think it's important and that "we don't see enough women out" and that sort of thing. So, you're a kid sitting down listening you kind of absorb it all in, whatever.

Most of these young women learned about health beliefs and values within a family environment as parents taught their children values and facilitated decision making. Health practices were established as mothers made appointments for their daughters, and these practices were reinforced when some mothers became role models for their daughters. When these women were uncomfortable talking to their mothers or when mothers were reluctant to discuss reproductive health, sisters or aunts provided the significant information that these women needed to make a decision. Some of the women in this study said that observing the activities of people with whom they had a close personal relationship influenced how they thought and made decisions.

The process of making a decision began as children observed and were guided in their health practices by their parents. Young women were encouraged to make simple decisions, and as they acquired significant information, they began to make more of their own decisions related to their health.

Peers as a source of significant information. While some of the women indicated that they learned about Pap tests in discussions with their mothers when they discussed birth control or from observing their mothers' health practices, this was not their only source of information. These young women also learned from each other because they were going through similar life experiences. There was a level of comfort that permitted young women to explore sensitive topics with each other. It was during these times of intimate peer to peer discussions that the topics of sexual intimacy and birth control were raised, and it was in the context of these topics that Pap tests were mentioned. The

following comment shows how a Pap test was talked about during these occasions:

> Yeah, it was just like. . . one of my friends had said she had just had a Pap test done. And a couple more you know just said how'd you find it. . . did you find it uncomfortable, cause it was a lot of their first times and mine too . You know . . . how was it type thing, just find out a little bit more about it. We just kind of discussed it like that a little bit and . . .

Another woman described how she and her friends talked about their experiences:

> . . . think it is talked about more at this level than it is back in high school. You are more open . . . I say to my friends like in another three months I have to get a Pap test again, like gross, right . . . We always talk about like being on the pill and what effects it has on our period and whatever.

It was during this overt activity of talking to peers that young women acquired significant information about having a Pap test. However, not all women chose to acquire significant information about the Pap test from their friends and blocked any discussion about this health practice. One woman clearly indicated her feeling to her peers:

> Well I knew later on I would have to have it done. Because the girls I was hanging around with . . . they was always saying, well I soon got to go for a Pap test and I said well I never ever had one done. And they said well it's awful uncomfortable. I said well don't tell me that stuff, I said you know, till I gets the experience of it first. Cause I didn't really want to know about it.

It was during these conversations with peers that women began to create an image of what the experience could be like. Few women were able to comment on their perception or their first experience of having a Pap test without using an adjective that denoted some unpleasant experience. One woman provided the label for Pap tests that seems almost universal. She said, "Oh there have been discussions about birth control pills

but not really about Pap tests. Some of them say oh I have to go for that dreadful thing but that is about it." Most discussions about birth control invariably led to mentioning the Pap test, and young women were able to share their brief experiences with their peers. These discussions set the tone for creating a perception that a Pap test was a "dreadful thing." Among these women, there was an understanding that "that dreadful thing" was a Pap test.

School as a source of significant information. School was a source of significant information for all of the participants, but it was more informative for those women who could not discuss reproductive health issues at home. One of the women said that reproductive health was not a subject that she discussed with her mother. While she did hear about topics such as menstruation and Pap tests from friends, most of her information about menstruation came during education sessions at school. For her, school became an important avenue for acquiring information:

> Well mom talked about it a little but she's not the type of person to sit down and talk about that stuff. So I was more just had to learn it all on my own. Talking to my friends and stuff like that. But probably when I was only eleven or going in twelve I started my period. And when I started I got frightened to death cause mom never told me much about it. So then after that she sat down and talked a little bit about it. But I mostly heard it from school and *Public Health Nurse* used to come in school and talk about it a bit. But other than that . . .

Others also identified school as an important place to hear about reproductive health and most women remember hearing about birth control and Pap tests during sessions in school. Depending on the age at the time of presentation, some of the sessions

evoked laughter and "giggles" from both young boys and girls. Still, for most, the school was the best place to hear about sexual health "because outside of high school there is not a lot of opportunity to learn about things like that you know what I mean." However, for one woman, this was not a topic that was discussed in school. She indicated that:

> . . . it was all romanticized as far as I was concerned. There was hardly very little factual information you know that you could rely on. Of course if you went to a Catholic school like I did, you weren't allowed to discuss anything that was too close to sex or that sort of thing, but . . . or your own body or whatever so.

Young women acquired significant information from the school, whether from the overt messages provided through information sessions or the covert messages communicated by the absence of discussion. Most of the women in this study said that what they remembered most about any information they received in school was not how to be healthy but how not to become pregnant.

Young women in this study acquired significant information from their family, peers and from the school, each adding to a repertoire of knowledge that would influence decision making. The strongest message acquired about reproductive health was "don't come home pregnant." This message was reinforced by the covert activities within the family and school and those overt activities that were clearly communicated. The strength of that message would have an influence on future health decisions, including the decision to have a Pap test.

Protecting Yourself

The significant reproductive health and decision making information acquired from

family, friends, or school reinforced the message of "don't come home pregnant." Whether this message was clearly communicated or subtly hinted, it became clear to most of the young women in this study that when they made the decision to become sexually active, avoiding pregnancy was paramount and that they had to protect themselves against an unplanned pregnancy. For most, protecting yourself against an unplanned pregnancy meant choosing to use oral contraceptives and most of the women in this study made the decision to use the birth control pill (BCP). This decision to use oral contraceptives required forethought and planning because this is a regulated method of birth control that can only be obtained with a prescription from a physician or nurse practitioner. Once the young women acted upon the decision to use oral contraceptives, they were introduced to the procedure of having a Pap test. All of the women in this study believed that in order obtain the BCP a woman must first have a Pap test.

Protecting yourself involved the following three themes: deciding to go on the pill, the price you pay, and the pill as a regulating mechanism. Deciding to go on the pill is illustrated by activities that were involved in making the decision to use the BCP. Once the decision to use the BCP was made, women believed that they would have to have a Pap test to receive their prescription. They considered the Pap test the price you pay for using the BCP to protect against an unplanned pregnancy. Finally, the young women indicated that the BCP became a regulating mechanism for remembering to schedule the Pap test.

Deciding to go on the pill. The decision to go on the pill was the step that initiated these women into the experience of a Pap test. Antecedents to this decision included a

sexual relationship, consultation, and discussion with others, such as family and friends, consideration of family values, and gynecological conditions. These antecedents will be considered in the following discussion.

Many of the women in this study indicated that the decision to use the BCP was reached when they perceived they had entered a significant relationship. If they anticipated that at some point they would be sexually intimate within this relationship, as a precautionary measure to prevent pregnancy, they decided to go on the pill. One woman who had a longstanding relationship and who considered becoming sexually intimate thought carefully about the implications of that decision. The decision to become sexually intimate carried consequences, one of which was becoming pregnant as shown by this quote :

> Well I was going out with this guy for over a year before I made the decision. Well the way that I looked at it if I wanted to involve myself in sexual relationships . . . I should be mature enough to take preventive measures.

The "preventive measures" referred to by this young woman meant that she would use the BCP to prevent an unplanned pregnancy. For all of the women in this study, when they spoke of "preventive measures" they were referring to protecting themselves from an unplanned pregnancy. It was this decision to protect themselves from an unplanned pregnancy that prompted the use of the BCP.

When the women in this study made the decision to use the BCP, they believed that in order to receive a prescription for the BCP, they would first have to have a Pap

test. This belief was reinforced when they visited the physician's office to obtain the prescription. The link between the prescription for the BCP and a Pap test was shown in one woman's comments:

> Well, I just entered in a relationship with my partner now and I wanted to go on the pill . . . but, I sort of made a decision that, okay, that I'm in this relationship now and we are having sex, it's regular, I thought I should go and get on the pill. So I had my first Pap test then.

Some of the women indicated that once the decision was made to go on the pill, they discussed it with their mother or sister. These are the women with whom they shared close personal information and with whom they believed they were able to express their thoughts freely. Inasmuch as there was open communication in many of the women's families, the decision to tell her mother that she wanted to go on the pill was described by one woman as ". . . probably the hardest thing that I had to do at that point in my life, go and say, mom I want to go and get on birth control." Even though some of these women were acting on the information they had acquired about preventing pregnancy and birth control, and despite the open communication and good relationship with their mothers, they found it difficult to talk about birth control with their mothers. One of the women said it was her older sister who recognized that she may need birth control and provided the information and support needed to make a decision to go on the pill. This young woman, who was attending university and sharing an apartment with her sister, described the following:

> I think it was the year when I first started university, I decided to get on the birth control pill. That was with the help of my sister. She told me that it

> was important to get a Pap test done. From that time on that is what I did every year.

The discussions with family or friends centered around the use of birth control, more specifically, the use of the BCP. Frequently, it was during these discussions that the requirement of having a Pap test was mentioned. The following comment reflected the reason most of the women gave for having a Pap test:

> So I probably got it done when I was 18. Like I think the reason was basically because I was thinking about going on the birth control pill. So it was like two together, rather than making my choice to have a Pap test. It was a choice to more or less to go on the birth control pill. It was a connection, I had no choice.

It was evident from the previous discussion that when these women became sexually intimate they considered pregnancy as one of the consequences of that decision. Most chose to protect themselves against becoming pregnant and reviewed their options for birth control. For some of the women in this study, the BCP was their initial choice of birth control.

However, not all of the women interviewed decided to go on the pill to prevent pregnancy. Some suffered menstrual irregularities early in the adolescent stage, and they protected themselves by seeking medical assistance for relief of these irregularities. For these women, the decision to go on the pill was made by the doctor as part of a treatment regime as can be seen from this statement:

> Well, with my periods every month I was having extremely bad cramps and I was 15 when I went, actually and that's when he put me on the pill. And . . . that's when I started to go for Pap smears cuz my cramps were so bad and . . . it just became a routine like every year and I haven't been off the

pill yet so . . .

While the reason for using the BCP was considered medical, these women said they also had a Pap test before their prescriptions could be filled. By the time these women made the decision to become sexually intimate, choosing a method of birth control was not a concern. They did not have to explain their reason for being on the pill to their family or peers.

Some of the women in this study delayed their decision to go on the pill. One woman who was sexually active said that even though she had discussed using the BCP and having a Pap test with her sisters she chose not to use this information and did not go on the pill. She was uncomfortable acting on this knowledge while she was still living at home because, as she said, "how do you get to the doctor, how do you tell your mother that you want to go for this particular test and why." She did not want her mother to know she was sexually active. It was only when her friend had an unplanned pregnancy that she decided to go on the pill and as a result had a Pap test as illustrated by the following comment, "The reason I went on the pill, I think, was because my best friend got pregnant . . . so I went and had my first Pap test."

Other women in this study who were also sexually intimate chose not to use any method of birth control and as a result became pregnant. It was this unplanned pregnancy and the desire to avoid future unplanned pregnancies that initiated the decision to go on the pill. Interestingly, these women did not talk to their mothers or sisters about being sexually active, and one woman had left school prior to any discussion about birth control.

These women did not have the opportunity to acquire the significant information from their family or school to assist in making a decision about their reproductive health prior to their pregnancy.

For most of the women, protecting yourself meant deciding to use the BCP and this decision meant that they would have to have a Pap test. The pill and the Pap test were seen as a package.

Being on the pill: the price you pay. The women in this study believed that one of the conditions for being on the pill was having a yearly Pap test. This was reinforced when women entered a physician's office to request the BCP and the physician would not issue a prescription until the woman had a Pap test. Receiving a prescription for the BCP was synonymous with having a Pap test. This was illustrated when one woman described her experience of requesting the BCP:

> Ah, well I said I wasn't going to have no more kids. So I said well I'll go on the pill. And then when I come home I went to the doctor and he told me that I had to get a Pap test done first. And I said well I said very good. So a couple weeks after that he made an appointment and I went up. Then after that he gave me the pill.

Women perceived having a Pap test as the price you pay for birth control pills. While some of the women had brief discussions with their mothers and peers about this procedure, they did not know how it would feel: thus they were not emotionally prepared for this experience. The impact was poignantly described by one woman:

> being on your back and you really feel like you . . . you're completely naked and it . . . all the things that you hate . . . like to me your body is very private and to have to take off your clothes and she'll do your breast

> examination and I am not the type of person who likes to be touched . . . it's really a terrible feeling to be on your back . . . your legs up in the air and the light shining on you . . . I mean . . . it's a completely cold and very unnatural.

Another woman depicted her experience with the following comment:

> I guess, just, ah, some other person was going to feel your genitalia and it was going to feel weird and different. Like it's an invasion of your own private area type thing and, even now after experiencing it, it's just that sensation of the speculum going in, like gross. It's not painful, it just gross.

Most of the women agreed that the procedure was not physically painful but that it was still an unpleasant experience, and some women described the procedure as leaving them with a sense of being invaded. The use of birth control had given women the ability to control their own reproductive lives. However, in order to be able to make that choice, a woman was compelled to have a Pap test. As a result, most women said that they "just want to get it over with" and "just give me the BCP and let me leave as soon as I can." They had no choice but to participate in a procedure that was intimate, invasive, and made them feel vulnerable. These women believed that they were required to have a Pap test to obtain the BCP. This was the price paid to use the BCP as one of the women so clearly states:

> ...other than knowing that I had to have one in order to get birth control and you had to have this test done once a year I think at that time, at age 17 or 18, No, I probably had no idea. No honestly, I don't think I knew why I was getting one . . . I think about . . . lots of women don't know this stuff you know they feel . . . if it's like me they feel it's the price to pay to get birth control because you don't see it in the way it benefits your health. You just see it as a chore, I guess.

This comment was not unlike many others as women reinforced the fact that the

procedure was "a dreadful thing," and given a choice they would omit having a Pap test. No matter how frequently they had a Pap test, the feelings of embarrassment and vulnerability experienced during the procedure were always present. However, having a Pap test was a necessary experience women had to undergo to receive the BCP.

While some of the women in this study indicated that they would prefer a female doctor or nurse do a Pap test, most felt the gender of the health care provider was not a concern. It was more critical to visit a physician with whom a trusting relationship had been established. Many of the women indicated that they were more at ease with the Pap test procedure when the physician was their family doctor who had been seeing them since childhood. Others suggested that the perceived accessibility of services, including access to confidential health care, would influence their decision to have a Pap test. Their decision would depend on where they could access health care and their confidence in the confidentiality of the service. One woman chose to leave the community to access health care. She described the reason for her choice when she said:

> . . . I guess I just know a little bit too personal basis what a lot of the staff here are like (meaning: she knew the staff personally) and I just don't feel comfortable. You know . . . I hear things . . . so I just prefer if my business wasn't here.

The issue of confidentiality may not be related only to the physician patient relationship since other people are in attendance at clinics. One woman gave her opinion why women may be concerned about accessing services in their community:

> I think a lot of it too sometimes, the staff you do have working in the clinic in a small town . . . probably is staff that is not as trained as a nurse or a

> physician. They don't realize that everything should be kept where it is heard. They may slip something to a friend or to somebody else. I think that is a lot of it.

These women were able to make the decision to go elsewhere for their health care services. For others, choosing to use the BCP meant that they had to access health care services in their own community even if they were uncertain about the confidentiality of their visit. This was the price they had to pay to obtain the BCP.

The pill as a regulating mechanism for the Pap test. Once the women in this study were using the BCP, the renewal date for their prescription became a mechanism by which they were reminded of the date they were due to have their Pap test. The women in this study said they were reminded to make an appointment with their physician to renew their prescription as the number of pharmacy refills decreased. It was their understanding that, when they made this appointment to renew their prescription, they were also making an appointment to have a Pap test. All of the women went regularly for a Pap test while they were using the BCP. Initially, the Pap test was associated with the need for the BCP rather than as a preventive health activity. However, the women indicated that over time they began to understand the benefits of having regular Pap tests, and they decided to include it as part of their health practice. For some, the need to renew their prescription for BCP continued to be a reminder to go for a Pap test. When one woman was asked what reminded her to go for a Pap test, she said: "Well to be honest my pills." Some women conceded that while they recognized that a yearly Pap test was an important part of a woman's health practice, they would be less "faithful" to a yearly schedule if not for

the need for BCP.

Once women stopped using the BCP they had to rely on other tactics to remind them to have a yearly Pap test. Some of the ways in which women remembered to schedule appointments with their physicians to have a Pap test included the anniversary of their birthday, the same month every year and significant life events. When one woman was asked how she remembered to go for a regular Pap test she said:

> How do I remember? For me it's every year in May. I don't know, I think about May, I guess because it was May I was leaving to go to university and it had been almost like the year was almost up. So I decided to do it with my own doctor before I went away.

While the majority of women continued to go for a Pap test, one woman who decided to discontinue the BCP because of side effects, also decided to stop having Pap tests. She believed that women only needed to have a Pap test while they were using the BCP.

In summary, the category of protecting yourself incorporated three themes: deciding to go on the pill, the price you pay, and regulating mechanism. These themes reflected the activities that women consciously decided to undertake to take care of themselves. For the women in this study, the requirement of having a Pap test did not deter them from using the BCP. They were taking care of themselves when they continued to use oral contraceptives and continued to undergo the experience of that "dreadful thing" in order to protect themselves against an unplanned pregnancy. Gradually, these women incorporated the Pap test into their health practices and the yearly renewal of the

prescription for the BCP served as a regulating mechanism that provided the opportunity for them to take care of themselves to protect against cancer of the cervix. For the women in this study, there was a strong association between using the BCP and having a Pap test. This was evident in the following comment by one woman when she said "for me it is the Pap test and birth control."

Changing Perceptions

The women in this study acquired significant information from a variety of sources but it wasn't until they decided to be sexually active and protect themselves from an unplanned pregnancy that they used this information and decided to use the BCP. Using the BCP provided these women with an opportunity to gather more information about the Pap test. They were introduced to the Pap test experience when they decided to use the BCP. The women believed that having a Pap test was a requirement for obtaining a prescription for the BCP. As these young women continued to share information with their family and friends, they gained more information about the reason for having a regular Pap test. In time, their perceptions about having a Pap test changed and they gained a new understanding about the reasons for having a Pap test. Changing perceptions can be described by the following themes: gathering more information and reaching a new understanding.

Gathering more information. Most of the women in this study described how they acquired significant information to assist with their decision to use the BCP. They initially linked having a Pap test with obtaining the BCP, and they were prepared to follow

through with this requirement for using the BCP. Once this decision was made they began to gather more information about the Pap test. Even though most said they had some information prior to having a Pap test, it was not until these women actually experienced the procedure that they realized they were not emotionally prepared for the impact the test had on them. This lack of preparedness is shown in the following comment:

> But, I guess, yeah, I was a little bit afraid, not really, I mean, I knew what to expect on an objective level like you know logically, I thought, okay, this is what can happen and you know what to expect . . . but I don't know how prepared you are emotionally until you actually do it.

Women agreed that although they understood the mechanics of having a Pap test, they were not prepared for the experience and could not have been prepared for the experience, regardless of the amount of information they had received. Understanding could only be acquired once a woman had gone through the procedure. One woman echoed those sentiments when she said "you have to experience it, that's for sure," when referring to having a Pap test.

Each woman in this study knew that within a year of starting the BCP she would have to return to her physician to have her prescription renewed and at that time would have to have a Pap test. In an attempt to prepare herself, and where there was open communication in the family, she would tend to ask for further information from her mother or sister. Frequently, this was supplemented with information from the physician. Some of the women looked to other sources of information. For example, two of the women said they received information by attending a health information session about

cervical screening. Others spoke about literature available at the physician's office. One woman said her anxiety abated somewhat when, at her initial visit for a Pap test, the doctor explained the procedure to her.

Other women had little information prior to their first Pap test. They had been made aware of the procedure and had been given a brief explanation of what to expect. One woman was given an explanation by the receptionist when she went to have her first Pap test. Another woman said it wasn't until some years after her initial Pap test that she was given a pamphlet in her doctor's office. It was when she read this pamphlet that she came to understand the reason for having a Pap test and what the procedure entailed.

One of the women was not able to openly discuss sexual health topics with her mother or family and did not talk about Pap tests with friends. She left the school system prior to high school and missed the information given to her contemporaries. When she decided to discontinue using the BCP, she also decided to discontinue having regular Pap tests, believing that they were not necessary. Opportunities to gather information about the Pap test were limited and contacts with the health care system did not provide her with the information needed to make a decision about having regular Pap tests. She was unable to gather the information necessary to make a decision about having a Pap test.

The experience of having a Pap test served as a learning opportunity for women as they came to understand what was involved with the procedure and the purpose of the procedure. For those women who had abnormal results from their Pap tests the importance of regular cervical screening was reinforced.

Many of the women in this study were able to recall experiences of friends or relatives who had abnormal cervical cells and cancer of the cervix. They knew women who had died from cancer of the cervix, and they could attribute this to the fact that these women had not had regular Pap tests. These women said that the knowledge that others had been diagnosed with cervical abnormalities prompted them to go for a Pap test on a regular basis. The women indicated that as they got older they become more aware and they talked more openly with friends and family. One woman who talked with her mother about Pap tests said:

> My mother, not that she told me I had to do it. It was just that she said it was better for me to go and make sure . . . My mother went through the same thing where she ended up with abnormal cells and that so it was a big eye opener.

Knowing that someone similar to yourself in age could have cervical abnormalities was an influence for one of the women who said "I think my opinion partially changed with regards to Pap smears too because of a close friend who had a scare . . . cervical cancer . . . " Another woman talked of the impact the death of her cousin from cervical cancer made on her decision to have regular Pap tests. Recalling the experiences of others who were sick or who had died influenced these women in their decisions about having a Pap test and ensured that they would continue to go for regular Pap tests.

These women gathered information with each discussion about Pap tests, with the health promotion pamphlets they reviewed, with personal experiences and as they recalled the experiences of others. Their commitment to take care of themselves by having a Pap

test regularly was strengthened as they continued to gather information. They understood the purpose of the Pap test and the health benefits of continuing this practice.

Reaching a new understanding. Most of the women in this study began having Pap tests as a condition for receiving the BCP. Their initial perception of the Pap test was that it was tied to the need for the BCP. Many changed this perception when they heard about the reasons for the Pap test, that is, to screen for abnormal cells and cancer of the cervix. However, this took time.

One of the women indicated that her reproductive health included a Pap test because at some time she wanted to have children. She understood the link between having a regular Pap test and early detection and prevention of cancer of the cervix. She knew it was critical to her health.

As the reason for having a Pap test changed, some women became more vocal about sharing this health information with others. They wanted women to understand the purpose of a Pap test and to make an informed decision to have a Pap test. They considered it an important practice for all women and became advocates for the procedure. One of the women who began having Pap tests to obtain a prescription for the BCP continued to have regular Pap tests because she was aware of the importance of this health practice. She changed her perception about having a Pap test and said she was "diligent about going now. I go every year like I said and I encourage my friends to go as well . . . "

As some of the women in this study began to understand the importance of having

a Pap test their perception changed and they no longer tied it to the need for the BCP. However, there was one woman who made the decision to discontinue the pill and discontinued having a Pap test. She was not aware of the reason for having a Pap test, nor did she have any personal experience with anyone who had abnormal cells of the cervix. She did not really understand the reason for having a Pap test and "just never bothered" to have a Pap test. She missed opportunities to acquire the significant information needed to make a decision about having a Pap test and did not have the opportunity to gather information to increase her knowledge. As a result she decided not to continue having Pap tests.

Initially, women had a Pap test as a condition for receiving the BCP. This initial practice was self limiting in that once the BCP was discontinued there was no mechanism compelling the women to have a regular Pap test. Gradually women's perceptions changed as they acquired the experience and knowledge about having a Pap test. They began to have a Pap test in order to screen for cancer. If the reason for having a Pap test did not change, then the process of incorporating this activity into a regular health routine did not occur. Women who have incorporated this activity into their health routine have reached a new level of understanding about the purpose of regular cervical screening.

Taking Care of Yourself- the Central Category

Taking care of yourself was the central category that described and linked the three categories of acquiring significant information, protecting yourself, and changing perceptions. Taking care of yourself was a continuous process that began when these

women acquired significant information from their family, peers and school. This learning process was gradual and was initiated when parents made health care appointments for their daughters and discussed health related matters. The young women assimilated the values of the family and used the information obtained from their mothers or other female relatives to begin to make health related decisions. While these women were being taken care of by family, the foundation for taking care of themselves was being established. These young women learned, from listening and observing the practices of others, that it was important to take care of your health. The significant information that these women acquired supported them in their ability to make health related decisions, particularly decisions related to using the BCP.

As these young women widened their circle of influence, they began to listen to their peers discussing sexually intimate topics which included the use of the BCP and the experience of having a Pap test. The Pap test was mentioned in relation to the use of the BCP and not as health habit to screen for cancer. In school, the use of birth control was discussed with pregnancy prevention. This information from peers and school added to a repertoire of knowledge upon which women could build and use to make decisions. Women were learning to take care of themselves. The initial focus of the information acquired was placed in the context of protecting oneself against pregnancy. Taking care of yourself meant protecting yourself from an unplanned pregnancy.

The significant information that these young women acquired from family, peers and school provided the support for their decision to take care of themselves by using the

BCP. All of the women in this study were introduced to their first experience of having a Pap test when they decided to obtain the BCP. While the decision to use the BCP was planned, having a Pap test was not.

Most of the women said they had some awareness of the procedure prior to their first Pap test. They indicated that discussions with peers created an image of an unpleasant experience, and they also said that these discussions did not prepare them for the emotional impact of the actual clinical procedure. However, these young women continued to have a Pap test despite having to experience what they called "that dreadful thing." They perceived that one of the conditions for using the BCP was having a Pap test. Whatever their reason for using the BCP, these women believed that having a Pap test was the price you pay for taking care of yourself.

Most of these young women continued to use the BCP and continued to gather more information. With added information and experience, the context in which having a Pap test changed from a perceived requirement for using the BCP to a health activity. When this happened, having a Pap test was incorporated into health practices. The young women who incorporated having a Pap test into their health routine had gained a new understanding of the importance of this procedure. They came to believe that making the decision to have a Pap test meant taking care of yourself to prevent cancer of the cervix.

The women who changed their perception about having a Pap test continued to attend to regular cervical screening. This change in perception occurred over time as women discussed having Pap tests and shared their experiences with each other. This

comparing of experiences stimulated questioning and searching for further information. Frequently, these young women supplemented the information they had obtained by reading health promotion pamphlets or talking to the family physician. Women became aware that having a Pap test was an important part of a health routine and one way to take care of yourself.

For those who did not have the advantage of a close personal relationship with their mother or who had left school early without the benefit of sexual health information, taking care of themself was difficult. When they made the decision to discontinue the BCP for health reasons, they discontinued having a Pap test. These women were unable to gather more information thereby limiting their understanding of the reason for having a Pap test. They did not receive encouragement to continue this health practice; therefore, the perception of the Pap test was still linked to the use of the BCP. These women were taking care of themselves while they were using the BCP and when, for health reasons, they decided to discontinue using the BCP.

Most of the young women in this study learned to take care of themselves as they acquired significant information and as they gathered more information. In the process, their perception about the rationale for having a Pap test changed. The amount of information these women were able to gather was varied and this variability influenced their ability to make health related decisions. Those who did not acquire the necessary information, did not change their perception about the Pap test and, as a result, did not make the decision to incorporate having a regular Pap test into their health routine.

The central theme of taking care of yourself described and provided linkages among the three categories: acquiring significant information, protecting yourself, and changing perceptions. While each of the categories was described in a sequential way, taking care of yourself showed how these categories intertwine. The women in this study described how they began the process of taking care of themselves when they made the decision to use oral contraceptives. Having a Pap test was regulated by this decision to use the BCP, whether it was for birth control or to alleviate menstrual discomforts. Over time, the women's perceptions about the reasons for having a Pap test changed and most of the women in this study said they wanted to "prevent things before they start or get worse", that is, they wanted to take measures to prevent or identify cervical cancer in the earliest stages. They had reached a new understanding of the importance of having a Pap test. With more information and experience this health screening activity was no longer considered a price to pay for using the BCP but came to be seen as a screening for cervical cancer and the price you pay to take care of yourself. As one of the women said, "a Pap test is one of the best things you can do for yourself."

Summary

In this chapter the findings from 14 interviews conducted with women aged 19-29 were described. These young women described how they acquired the information from their family, peers and school that assisted them in their ability to make decisions. For most, it was the decision to use the BCP that introduced them to the experience of having a Pap test. The information acquired reinforced the decision to protect oneself from

pregnancy. Most of the women chose to use the BCP and, in doing so, understood that they would be required to have a Pap test to receive a prescription for the BCP. Initially, these women considered having a Pap test "the price you pay" to protect themselves against an unplanned pregnancy. As perceptions changed, having a Pap test came to be seen as protection from cervical cancer.

As the young women in this study gathered more information to add to their repertoire of knowledge, most became more knowledgeable about health related activities, especially about the importance of having a Pap test. This was a gradual process that was supported by each of the activities described in this chapter. The findings described in this chapter reveal the covert and overt activities that influence how young women made decisions about taking care of themselves and how these decisions influenced them to have a Pap test.

In the next chapter, these findings will be discussed in relation to the literature.

Chapter Five

Discussion

The findings from this study showed how young women made decisions about having a Pap test. The three categories of acquiring significant information, protecting yourself, and changing perceptions emerged from the data to show the phases of how women are influenced to make decision to have a Pap test. The central category of taking care of yourself explained the relationship among the three categories. In this chapter, the findings will be discussed in relation to the literature.

Acquiring Significant Information: Influence of Family, Peers and School

The young women in this study acquired significant information that provided support for making a decision about using birth control and having a Pap test from their family, peers, and school.

Family. In the current study, the findings revealed the role of the family in teaching values, establishing health screening activities, and providing guidelines for decision making. Young women learned about health beliefs, health practices, and family values about sexual behavior within a family environment. The messages conveyed to the young women through covert and overt activities provided a foundation for future decision making. The importance of open communication between adolescents and their parents has been discussed in the literature, mostly in relation to adolescent sexual risk taking behavior (Hutchinson, 1999; Miller & Whitaker, 2001). When parents have clearly

communicated their disapproval of sexual intercourse, adolescents delayed initiation of sexual intercourse (Rosenthal et al., 2001). Other studies have identified that open communication and discussions with young women had a positive influence on the use of condoms and other contraceptives (DiClemente et al., 2001; Miller & Whitaker, 2001). These studies supported the benefit of open communication between parent and adolescent and that this open communication contributed to safer sexual practices.

In this study, the mother in the family was the primary communicator about sexual health issues. Daughters who were able to openly discuss the use of birth control with their mothers, also had the opportunity to acquire information about having a Pap test. This open communication was an avenue to learn about sexual health. The support, advice and guidance received from their mothers provided direction for future decision making. As Miller and Whitaker (2001) noted, open communication, particularly with the mother, facilitates positive health seeking behavior. This finding was also supported by Burak and Meyer (1997) who found that the majority of college women, when asked about possible prompts to having a Pap test, indicated that their mother had talked to them about the procedure. This is similar to other studies that also reported that the mother is the member in the family most likely to discuss sexual health information with their children (Miller, Kotchick, Dorsey, Forehand, & Ham,1998; Walker, 2001). As well, young women observed their mothers going to the doctor for a Pap test and this action had a positive influence on them. Najem, Batuman, and Smith (1996) found a direct association between having a Pap test and young women's awareness that a family member had undergone a

Pap test. Other research studies have also found that mothers' health behavior and lifestyle have an influence on their daughters' health seeking behavior (DiClemente et al, 2001; Gillis, 1994; Schreck, 1999).

The young women described how family discussions about sexuality often reflected the family values related to young unmarried women being sexually intimate. There was little discussion about the use of birth control or other issues related to sexual health such as the risks associated with sexual activity at an early age or the need to limit partners. This finding is consistent with other studies that identified that frequently the content of parent-adolescent conversations focuses on the negative outcomes of sexual activity (DiIorio, Kelley, & Hockenberry-Eaton, 1999; Jacard & Dittus, 2000).

Parents are in a unique position to influence their children by providing health information and fostering decision making skills. Consistent with other studies (DiIorio, Kelley, & Hockenberry-Eaton, 1999; Jaccard & Dittus, 2000; & Rosenthal et al., 2001), the present study also identified the importance of open communication between parents and adolescents about sexual health issues. Parents can influence their daughter's health if they communicate openly and demonstrate positive health behaviors. The pattern of open communication should be established early so that it is well established by the time a child enters the adolescent developmental period. It may be difficult to initiate discussions about sensitive topics, such as sexual activity and birth control, in the adolescent period if a pattern of open communication has not been established. Those studies that considered adolescent-parent communication indicated that, in families where communication was

limited, young women initiated sexual intercourse at an earlier age and their use of birth control was irregular (DiClemente et al., 2001; DiIorio, Kelley, & Hockenberry-Eaton, 1999).

Peers. In this study, the topic of having a Pap test was raised during times of intimate peer to peer discussion about sexual intimacy and birth control. This sharing of information with peers contributed to their knowledge and to the perception that the Pap test was a "dreadful thing." While these discussions with peers influenced the perception about the experience, the discussions did not seem to influence their choice of birth control. This would indicate that these young women selectively chose the information they needed to make a decision and that they considered the implications of their decisions. Other studies have shown that peers have a stronger impact on lifestyle choices such as smoking and drinking, but parents influence basic values and life goals (Lau, Hartman, & Quadrel, 1990; Ouellette, Gerrard, Gibbons, & Bergan, 1999). This was evident in this study as young women made the decision to continue using the BCP and having a Pap test rather than risk an unplanned pregnancy.

While few studies have discussed peer influence about the decision to use the BCP or to have a Pap test, there is support in the literature for the influence of peers on other health related decision making. Sevin (1999) suggested that peer relationships have a powerful influence on behavior in the adolescent years. This influence has been discussed in relation to health behaviors such as seat belt use, alcohol use, and sexual activity (Keller, Duerst, & Zimmerman, 1996; Lau, Quadrel, & Hartman, 1990; Ouellette,

Gerrard, Gibbons, & Reis-Bergan, 1999; Riccio-Howe, 1999). There is evidence to show that it is the perception of peer norms that has a strong influence on activities. For instance, young women who perceived their peers to be sexually active were more likely to have intercourse at an earlier age (Keller, Duerst, & Zimmerman, 1996). There are few studies, however, describing discussions about sexuality with friends and the impact of these discussions on sexual attitude and behavior (DiIorio, Kelley, & Hockenberry-Eaton, 1999).

School. Sexual health education for intermediate and high school years is not a compulsory part of the school curriculum within the western region of Newfoundland, and the teachers who are providing sexual health education may lack knowledge in the areas of health and sexuality. The nature of the information that is provided to students and the amount of class time given to health education is dependent on the school board, the school and the teachers, and therefore this information is varied. Some of the women in this study indicated that the school provided the opportunity to add to their knowledge about sexual health while others indicated that the information they remembered receiving in school was inadequate for their needs. Information about sexual health was often approached from the perspective of avoiding pregnancy and not how to take care of your health. This approach frequently reinforced the family values related to sexual activity and unplanned pregnancy. For the young women who were able to acquire information from their mothers or peers, school was not considered a main source of information. However, for those women who did not discuss sexual activity and other related topics at home and

were not comfortable talking to peers, the school was a source of significant information. Adolescents who have access to accurate sexual health information frequently make safer, more responsible choices (Jadack & Keller, 1998) suggesting that in the absence of open communication within the family, the school may be able to provide the information young women need to make decisions.

In this study, women acquired significant information from a variety of sources and these sources of information presented a narrow perspective of women's health by focusing on preventing pregnancy. These sources did not broaden young women's knowledge about their health or inform them about the importance of having a Pap test. As long as the focus of sexual health remains on avoiding pregnancy, opportunities to learn about reproductive health are limited. Other studies have shown that women do not have sufficient knowledge about cervical cancer screening or the risks of cervical cancer (Burak & Meyer, 1997; Kahn et al, 1999; McKinley & Billingham, 1998). The focus on avoiding pregnancy suggests that women are making decisions about their reproductive health without all the information needed to make an informed decision.

Protecting Yourself

Young women acquired significant information from their family, friends, and school. They were able to use this information to make decisions about sexual intimacy and pregnancy. Most of these women understood the consequences of becoming sexually active and the need to protect themselves against an unplanned pregnancy. These young women began to make decisions, first to protect themselves against an unplanned

pregnancy or to alleviate menstrual discomforts, and later to protect themselves against cancer of the cervix.

Deciding to go on the pill. All of the women in this study made a decision to use the BCP. For most of these women, this decision to use the BCP introduced them to the experience of having a Pap test. They believed that they were compelled to have a Pap test if they wanted to use the BCP. This perception that a Pap test was a requirement for obtaining the BCP has been identified by other women in studies that explore attitudes to cervical screening (Bush, 2000; Fitch, Greenberg, Cava, Spaner, & Taylor, 1998). As a result of this perception, young women did not have an understanding of the purpose for cervical screening or the benefits of regular cervical screening. This procedure was viewed as necessary to obtain oral contraceptives.

Guidelines for cervical cancer screening in Canada recommend that an initial smear be obtained from any woman over the age of 18 who has had sexual intercourse, while women who have never had sexual intercourse do not need to be screened (Miller, 1991). The Pap test is a health screening procedure that is recommended for women who are sexually active and is not tied to the use of the BCP. This misconception about the need to have a Pap test as a requirement for obtaining the BCP may influence a woman's decision to continue having a Pap test once she decides to discontinue using the BCP. Young women need to have the information about cervical cancer screening and cervical cancer risk factors to enable them to make an informed choice about going for a Pap test.

The price you pay. While some of the women had discussions with their mothers

and peers about the procedure, they did not really know what to expect prior to their first experience of having a Pap test and were emotionally unprepared for this experience. The Pap test is physically uncomfortable, embarrassing and places a woman in a vulnerable position. The emotional anxiety associated with going for a Pap test as well as a sense of being invaded and feeling very vulnerable was described by several women. Domar (1986) suggests that the Pap test is one of the most common anxiety producing medical procedures and that women may intellectually consent to the procedure but they never emotionally consent. That the examination causes embarrassment and anxiety for some is understandable because it necessitates behavior inconsistent with the traditional family values that were learned in the home. In this study, women considered this intimate procedure the 'price you pay' to receive the BCP. Continuing to have a Pap test once the BCP is discontinued is the "price you pay" to stay healthy. It is a necessary activity that women must endure for their health.

For the women in this study, the benefits of using the BCP outweighed the discomforts associated with having a Pap test and they continued to have Pap tests in order to receive their prescription for the BCP. These findings are in contrast to those of Langille, Graham, and Marshall (1999) who found that fear of having a Pap test became a barrier to using oral contraception for the young women who participated in a study to determine barriers to accessing and using sexual health services. Other studies have also identified fear and embarrassment as potential barriers to participating in cervical cancer screening (Burak & Meyer, 1997; Neilson & Jones, 1998; Ibbotson & Wyke, 1995).

For many of the women in this study, the relationship they had with their health care provider was important to their comfort while attending for cervical cancer screening. Many of the women had a longstanding association with their family physician resulting in an atmosphere of trust and confidence, which served to reduce some of the anxiety associated with having a Pap test. The ability to establish trust and rapport with the physician has been identified by adolescents as important (Kahn et al., 1999). In this study, the young women did not have a preference for the gender of the healthcare provider. This is in contrast to most of the studies about cervical cancer screening which indicate that women would prefer a female provider (McKie, 1993; Neilson & Jones, 1998).

These women placed more emphasis on being able to access services that were confidential. Some women chose to access services in another community rather than risk the loss of privacy that some women associate with attending to health care in their own community. For others who were unable to travel to another community, this was a price you pay for taking care of yourself. Concerns about issues of confidentiality and lack of privacy, especially in rural areas, have been cited as potential barriers to obtaining sexual health services (Stewart & Rosenthall, 1997; Warr & Hillier, 1997).

The pill as a regulating mechanism. The findings from this study suggested that women who understand the importance of having a Pap test will find a mechanism to remind them to make an appointment to schedule a Pap test. For many of the women, associating the need to renew the prescription for the BCP with the timing of a Pap test was a useful strategy to remind them of this health practice. The women who understood

the importance of regularly scheduling a Pap test used other strategies to remind themselves to have a yearly Pap test when they stopped using the BCP. Research studies that have addressed the issue of providing a mechanism to remind women to have a Pap test have focused on the women who do not regularly attend to cervical screening (Buehler & Parsons, 1997; Ibbotson & Wyke, 1995). These studies have considered call-recall systems and sending invitations to invite women to be screened and have found that these methods alone may not be effective in increasing attendance. None of the women in this study relied on a health care provider or the health care system to remind them to take care of their health. Women who have acquired the information necessary to make a decision to have a Pap test will develop their own mechanisms for remembering to have a yearly Pap test.

Changing Perceptions

Young women in this study began to have regular Pap tests as a requirement for obtaining a prescription for the BCP. Over a period of time, they acquired significant information that would be used to make health decisions, including those related to cervical screening. As they gathered more information, their reason for having a Pap test changed and their perception about this health practice changed.

Gathering more information. The yearly encounters with the physician provided an opportunity to gain familiarity with the Pap test procedure. Some of the women took this time to read the literature that was available in the physician's office, and some physicians took the time to explain the procedure in an attempt to decrease the anxiety

associated with having a Pap test. Other women gathered information at public sessions about cervical cancer screening. However, none of the women in this study could recall posters or media presentations about cervical cancer screening.

These young women talked to their mothers about birth control, and mothers shared personal information about their own experiences in an attempt to educate their daughters about the benefits of having a Pap test. Daughters recognized the significance of their mothers yearly visits to the physician. For some of the women, the abnormal results of their own Pap tests and the required follow-up reinforced the importance of having regular Pap tests. These encounters with the health care system and discussions with their mothers served to increase their knowledge about cervical cancer screening.

Several women could recall the experience of a friend or relative who had experienced abnormal Pap test results. Some women knew of women who had died of cervical cancer, and they attributed this to the fact that they had not had regular Pap tests. These young women were gathering more information about the benefit of having a regular Pap test and were made aware of the ramifications of not having regular Pap tests. Developing an understanding and personal view about the importance of regular cervical cancer screening was enhanced when women knew other women who had cervical abnormalities or cancer. This knowledge became a factor in motivating these women to be diligent about making the decision to have a Pap test. Other researchers have found similar results; the experiences of close friends or relatives may influence a persons perception of risk for an illness and thus their attention to screening practices (Boyer, Williams,

Callister, & Marshall, 2001; Chalmers & Thomson, 1996).

Reaching a new understanding. Although most of the women agreed that the Pap test was not painful, they still perceived it to be "that dreadful thing." However, now this procedure was more meaningful as a health practice because these women understood that they had to protect their health. They tolerated this procedure because they recognized it as an important component of women's health practices.

As can be seen from this study, there was a gradual change in the perception about the reasons for having a Pap test. Women incorporated new information and used that information to make decisions about health practices. These young women became diligent about attending to cervical cancer screening and shared this information and their own experiences with their friends, as their mothers had done. They were becoming advocates for regular cervical screening. This level of acceptance was actually adopting a practice of self care aimed at early detection of cancer. This is not unlike women who may be at risk for breast cancer and, having assessed their risk of disease, adopt screening practices to protect themselves (Chalmers & Thomson, 1996). Women used the information to evaluate the importance of having a Pap test.

Taking Care of Yourself

The process of taking care of yourself can be described as a series of activities that propel women toward taking an active role in maintaining their reproductive health. Taking care of yourself involved making decisions. Developing the skill of decision-making was a gradual process that followed a sequence of making small decisions which

were validated. Young women continued to build on the decision making skills as they continued to make decisions, thus taking care of themselves. This study illustrated that taking care of yourself was a learned process that began when these young women were children and they learned about health practices and beliefs in a family environment. These findings have been supported in the literature that describes self care activities as those that are learned according to beliefs, habits, and an individual's cultural environment (Orem, 2001).

As young women made the decision to become sexually active, most recognized the need for birth control. They made the appointments with their physicians, obtained the prescription for birth control, and followed the protocol to ensure they were protected against pregnancy. They were beginning to take an active role in the decisions that affected their lives. Part of the process of taking care of yourself is that ability to select and to use the information acquired to make a decision. These actions are the overt activities that indicate that women have the information they need to make a decision at this time in their lives.

Taking care of yourself can be defined as taking action to contribute to one's own health (Kickbush, 1989). These women were taking care of themselves by establishing a pattern of regular attendance for cervical cancer screening. As they came to understand the rationale for the procedure, the possibility of cervical cancer was brought to the forefront and became real. These young women were taking care of themselves to prevent cervical cancer. As these women gained knowledge and experience, they changed their

perceptions about the rationale for having a Pap test and recognized the importance of regular cervical screening. Taking care of yourself focused on what the women perceived as their needs and goals at the time.

The relationships with family and friends supported most of the women in building decision making skills, and a foundation for future decision making was being established. The women learned to take care of themselves in different ways. Some acquired information from family or friends. As they gathered more information, others actively searched for information by reading pamphlets or asking questions during their health care visits. Women who adopt self care practices have evaluated their risk and made a decision about their health (Chalmers & Thomson, 1996).

The findings from this study described how the women who had the opportunity to acquire information, to share experiences with others, and to gather more information were influenced to make a decision to have a Pap test. If the supports that facilitate the ability to gain a new understanding about the rationale for having a Pap test are not in place, women may take a longer time to understand the importance of this health practice and delay having regular Pap tests.

The process of taking care of yourself can be placed on a continuum that began with the covert activities of acquiring information and gradually moved to those overt activities that indicated that having a Pap test was incorporated into a woman's health routine. Self care activities are usually preventative activities, they have a purpose and a pattern (Orem, 2001). In this study, taking care of yourself became a pattern that women

established to contribute to their own health.

Summary

In this chapter, the themes that emerged from the data were discussed in relation to the research literature. The findings from this study were consistent with the research studies that reported the importance of open communication within families. Open communication facilitated learning and influenced decision making, especially as it related to sexual activity. Understanding the purpose and benefit of having a Pap test will ensure that women will take care of themselves by attending to regular cervical cancer screening.

Most of the research studies about cervical screening have focused on the barriers to regular screening and strategies to overcome these barriers. The findings from this study reflect what has previously been reported in the literature, particularly in identifying the importance of acquiring knowledge to facilitate health behaviors. This study reinforces the importance of ensuring women have the knowledge to make an informed decision. When the women in this study had the knowledge, they made a decision to have a pap test. They made a decision to take care of themselves.

The findings from this study have implications for nursing practice, nursing education, and future research and these will be described in the following chapter.

Chapter Six

Nursing Implications, Limitations of the Study, and Conclusion

The purpose of this study was to explore the underlying social processes that influenced young women to make a decision about having a Pap test. Using a grounded theory approach fourteen women were interviewed and these interviews provided the main source of data. The analysis of the data revealed three categories that described the decision making process: (1) acquiring significant information, (2) protecting yourself, and (3) changing perceptions. The central category that explained the relationship between the other three categories and linked these categories together was identified as "taking care of yourself."

The findings generated from the grounded theory approach will contribute to the body of knowledge about how young women between the ages of 19 and 29 make decisions about having a Pap test. The processes that underlie the social experience of "taking care of yourself" were discovered. These can become a basis for nursing interventions designed to increase the uptake of cervical screening in young women in Newfoundland.The women described how they progressed from knowing little about having a Pap test to understanding the importance of having a Pap test. When these women changed their perception of the rationale for having a Pap test, it became part of their regular health routine. This final chapter is divided into three sections. The first section outlines the implications of this study for nursing practice, nursing education and

nursing research. This is followed by the limitations of the study and a brief conclusion.

Implications for Nursing Practice, Nursing Education, and Nursing Research

Implications for Nursing Practice

From the findings in this study, young women identified that communication within the family influenced health behavior and decision making. When there is open communication in the family, women have an opportunity to acquire information that will assist them with their decision making. Nurses can facilitate the development of communication skills that will enable parents to feel comfortable discussing health topics with their children. This can be accomplished through the promotion and delivery of parenting information sessions that are directed toward families with young children or families with adolescents. These sessions could provide factual information about specific health topics as well as describe ways parents can communicate with their child. Providing an opportunity with parents to meet and share information with each other is another mechanism for facilitating skill development.

Each encounter with the family must be considered an opportunity to assess communication skills and family interaction. Based on this assessment, nurses can guide parents in their development of communication skills by suggesting ways to introduce age appropriate health topics. The concept of sexual health education can be introduced to parents early in their parenting experience so that they can develop the skills for open communication.

In collaboration with community partners, such as family resource centres, church

groups, or the YMCA, nurses may provide resource material or look for the opportunity to offer education to individuals or groups. For example, providing education during community recreational events may allow some parents an opportunity to learn about communicating with their children. In this way, those families that traditionally do not avail of parenting classes or childbirth education may have access to information.

Programs that enhance parent-teen communication about sexual health may be effective in developing skills to discuss potentially sensitive issues. Nurses can collaborate with other professionals in the community, such as the school guidance counselor, to promote or to facilitate the delivery of these programs. Parents and teens can be brought together in an informal setting to explore their relationship and communication patterns.

The influence of mothers and sisters was noted to have an impact on a young woman's decision to have a Pap test. Mothers, sisters, and other female relatives were role models for young women. Nurses can build on the close relationship between mothers, sisters and young women during health promotion activities. As nurses plan for health promotion and health education, they need to consider that providing information to older women and increasing their attendance to cervical screening may indirectly influence whether the younger relatives decide to have a Pap test. Mothers, sisters, and other female relatives can be invited to attend education sessions, whether these sessions are delivered in the school or another community setting.

Friends discuss sexual health issues and provide each other with information and direction. Health education could be delivered by an informal method that supports the

opportunity for group discussion and questions. Peer led, nurse facilitated, activities could be considered when planning activities for young women.

Many of the communities in Newfoundland have local cable television stations. Information can be shared through this medium. Cervical cancer screening may be promoted with advertisements developed by community health providers, the provision of health education in the form of videos, or by having the nurse participate in an on-screen interview about women's health issues.

The young women in western Newfoundland wanted access to resources and information to enable them to take care of themselves and make healthy choices. The school is one setting that the young women identified as a source of information. The variability of the health information provided suggested a role for nurses in providing health education in the schools. Following a needs assessment conducted with young women in schools, health promotion activities can be provided. Nurses who have access to the school setting can advocate for health education and collaborate with school personnel and parents to encourage health education opportunities.

Literature could be distributed throughout the community in those places women frequent; for example, the grocery store, drugstore, hairdresser, dry cleaners, and libraries. This would provide the opportunity for many women to have access to health information outside of the school setting.

The findings from this study suggest that if women have accurate information they may make the decision to have a Pap test. At each client contact, health teaching can be

provided to reinforce positive health practices. If cervical cancer screening literature is available in waiting rooms, women and men will have an opportunity to gain information. The opportunity for health teaching about cervical screening may present itself when women are admitted to the hospital and a thorough nursing history is completed. This encounter can be used to assess health practices about having a Pap test. Nurses can then provide information to women based on their educational needs and can also reinforce the importance of regularly attending to cervical screening. The nurse can also remind the physician if the woman is delayed in obtaining a Pap test.

Many women talked of being emotionally unprepared for the experience of having a Pap test. Nurses who are providing women's wellness clinics should offer the opportunity for women to discuss their anxieties prior to the procedure and allow time for questions. Explaining the procedure each step of the way may reduce anxiety for some women and may reduce the perception that the Pap test is a dreadful thing. In communities where cervical cancer screening rates are low, nurses can advocate for women's wellness clinics. Offering Pap test clinics, in collaboration with other health providers, and presenting these clinics as a social, as well as health activity, may decrease some of the anxiety about going to a physicians clinic. Encouraging all women age 18 and over to attend may increase the perception that this health practice should be a part of every women's health routine.

The issue of confidentiality between health professionals and community members was identified. Nurses must reinforce, to their clients, that their practice is confidential and

that any topic discussed will remain confidential, within the parameters of the regulating agencies.

Implications for Nursing Education

Nursing education, with one of its main focuses on health and health promotion, has an opportunity to enhance the skills of future nurses in the area of population health promotion and program development related to women's health. Nurse educators will need to teach students about the many factors that influence health and health seeking behavior.

The findings from this study suggest that health values are developed early, within a family environment. The role of health promotion frameworks within health assessment courses can be emphasized so that nurses can develop those skills necessary to assess family health promotion patterns and family dynamics. This assessment information will be used to develop a plan for health promotion within a family environment and support parents in their efforts to teach their children. Nurse educators will need to teach students to be sensitive to the family's perception of sexual health and to the values and beliefs that are held within a family. Nursing students will need to be taught to be sensitive to a woman's history and to examine their own beliefs and values which may affect the manner in which they provide information.

In this study, women described the influence of their families on the development of health values. Female relatives and friends influenced their decisions to have a Pap test. They also recalled the information they received in school. Sexual health cannot be

considered in isolation of women's experiences, and nursing students need to understand the factors influencing the development of healthy behaviors both within the individual and at a social or environmental level. Nursing students need to be taught the ways in which women learn about health so that the health promotion activities are relevant to the age. Nursing educators must provide students with information about confidentiality and ethical responsibilities concerning safeguarding client information.

The young women in this study described the feelings of vulnerability they experienced when having a Pap test along with the perception that they did not have a choice to have a Pap test if they wanted to use the BCP. Nursing educators need to teach students how to support women to be advocates and become empowered to take care of their own health. This is especially important within the area of sexual health and specifically within cervical cancer screening, which places women in a vulnerable position physically and emotionally.

Nursing educators should prepare students for their role in community development. Nursing programs need to focus curriculum development on a population health perspective. Collaboration with community, partnerships with schools, service groups, and other health care providers are necessary to ensure that women reach a new understanding about having a Pap test. Students must develop those community assessment skills that will enable them identify those resources in the community that will support and enable them to practice collaboratively.

Implications for research

Several women attributed their adherence to regular cervical screening to the influence of their mother and the health values learned in a family environment. Research studies that are directed toward understanding how families influence the development of health values could be conducted with young women and families.

Findings from this study revealed that most of the sexual health information was acquired while these women were adolescents; however, there was little discussion with family or peers about the risks associated with sexual activity at an early age or the need to limit partners. Nursing studies are needed to assess the knowledge of risk factors and protective measures against STD's, HPV, and cervical cancer.

The considerations that women give to initiating sexual activity, to deciding which method of birth control to use or to future plans for having children influence the way they take care of themselves. These findings point to a need for more comprehensive research about the antecedents of health protective behaviors.

The results of this study indicated that the majority of women had their initial Pap test as a prerequisite for obtaining the BCP. Further investigation is required with women, who choose not to use birth control or who choose another method of birth control, to determine how these women make a decision to have a Pap test.

Research is required to identify those prevention and intervention strategies that are most likely to influence whether young women attend to cervical screening. This information is critical for recruiting women into a cervical screening program and to

encourage women to incorporate having a Pap test into their regular health routine.

In contrast to other studies, most of the women indicated that gender of the provider was not a problem. The women in this study indicated they were more comfortable with the family physician they had been seeing since childhood and that they wanted a trusting relationship with their physician. Nursing research is required to examine the issues of access to service in rural Newfoundland, where physician services may be limited or frequently changing. Nursing research could be completed to compare the cervical cancer screening rates in communities that have introduced nurse practitioner services to those communities where the physician is the service provider.

This study explored one aspect of young women's health, how young women make a decision to have a Pap test. Further research with this group of young women is recommended to further examine the process of taking care of yourself. A broader perspective that includes the social, environmental, and community contexts may lead to further understanding of how young women take care of themselves.

Limitations of the Study

One of the limitations of this study is that the researcher is a novice in the method of grounded theory. This may have influenced the quality of data collection and analysis, and therefore the density of the categories. A second limitation of this study is that theoretical sampling was limited to a group of Caucasian women ranging in age from 19-29. These women were recruited from a small rural population, less than 90,000 people, on the west coast of Newfoundland. Education level varied but most of the women had

completed grade twelve or had post secondary education. Socio-economic status was not requested in the demographic information.

Conclusion

The purpose of this study was to determine how young women in western Newfoundland, ages 19-29, make decisions about having a Pap test. A grounded theory approach was used and interviews with 14 young women provided the major source of data. A discussion of the findings was presented and in this final chapter of the thesis, the implications for the nursing profession were addressed and limitations of the study identified.

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Appendix A

Advertisement

Are you willing to talk about personal health issues???

Are you female, 19-29 years of age, living in western Newfoundland and willing to participate in a research study?

I am a graduate student in the Masters of Nursing program at Memorial University of Newfoundland. I would like to interview young women between the ages of 19 to 29 to find out how they are influenced to make decisions about taking care of their health. I am particularly interested in Pap testing. The information obtained from this research may be used to plan programs to meet the needs of young women.
There will be one interview which will be audio-taped and possibly a second interview for clarification. Confidentiality and anonymity will be ensured.

If you think you might be interested, please call Heather Taylor at) for further information.

Appendix B

Letter to Assistant Chief Executive Officer-Community Health Division

January 22, 2000.

Ms. M. Fleming
Associate Executive Director
Community Health Division
Health and Community Services Western

I am a student in the Master of Nursing Program at Memorial University of Newfoundland and as part of the degree requirement I have to conduct a research study. My focus for this program has been cervical screening. I am particularly interested in young women and the management of health as it relates to cervical screening. The main objective of this study is to determine how young women, ages 19-29, make decisions about having a Papanicolau test.

I am requesting permission to contact public health nurses in the western region, who will be approached to assist in identifying and acting as initial point of contact for young women. I am interested in interviewing women who meet the following criteria: 1) between the ages of 19 and 29, and 2) are mentally competent, able to read, and speak English.

Complete anonymity will be assured and those who agree to participate will be given the option to withdraw from the study at any time. Approval for this research has been received from the Human Investigation Committee (HIC), Memorial University of Newfoundland.

The results will be made available to you following completion of the thesis. If you have any questions or concerns please contact me at Thank you for your consideration to this request and I look forward to your reply.

Sincerely

Heather Taylor B.N., R.N.

Appendix C

Letter from Assistant Chief Executive Officer- Community Health Division

P.O. Box 156
Corner Brook, NF, A2H 6C7

January 31, 2000

Ms. Heather Taylor;
Student

A0L 1K0

Dear ~~Ms. Taylor~~ Heather:

Permission is granted to contact public health nurses of Health and Community Services Western as a component of your research study. This permission is given with the understanding that public health nurses will participate voluntarily and there is no access to the organization's files and/or documentation for the purposes of your research.

I trust that this is satisfactory. Good luck in the completion of your Master of Nursing Program.

Sincerely,

Marilyn Fleming
Assistant Executive Director
Community Health Division

MF:mb

Appendix D

Consent to Participate in Nursing Research

FACULTY OF MEDICINE - MEMORIAL UNIVERSITY OF NEWFOUNDLAND
AND
HEALTH CARE CORPORATION OF ST. JOHN'S

Consent To Participate In Health Research

TITLE: How Young Women Make Decisions About Cervical Screening

INVESTIGATOR(S): Heather Taylor B.N. M.N (candidate)

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or you may withdraw from the study at any time without affecting the care you may receive from any health professional.

Information obtained from you or about you during this study, which could identify you, will be kept confidential by the researcher. This information will be kept in a locked cabinet and only the researcher will have the key. Your name will not appear on any of the documents. The investigator will be available during the time the study is in process should you have any problems or questions about the study.

The purpose of this study is to determine how young women make decisions about having a cervical screening test for cancer (Pap test). The information obtained from this study may be used to design programs that will encourage women to have a Pap test.

You are asked to participate in one interview that should take 1-1½ hours. You may be asked to return for a second interview. This second interview should take about 30 minutes. You may stop either of the interviews at any time if you become uncomfortable. The interviews will be audio-taped and then the interviews will be typed. The audio-tapes will then be erased.

I will be interviewing other women and anticipate that this study will take a year to complete. You may have a copy of the final report when it is available.

There are no anticipated risks or discomforts. The only inconvenience to you by your participation in the study is the time needed for the interview. The results of this study may be of benefit to young women.

Liability statement.

Your signature indicates your consent and that you have understood the information regarding the research study. In no way does this waive your legal rights nor release the investigators or involved agencies from their legal and professional responsibilities

Signature Page

Title of Project: How Young Women Make Decisions About Cervical Screening

Name of Principal Investigator: Heather Taylor B.N. R.N.

To be signed by participant

I, , the undersigned, agree to my participation in the research study described above.

Any questions have been answered and I understand what is involved in the study. I realise that participation is voluntary and that there is no guarantee that I will benefit from my involvement.

I acknowledge that a copy of this form has been given to me.

(Signature of Participant) (Date)

(Signature of Witness) (Date)

To be signed by investigator

To the best of my ability I have fully explained the nature of this research study. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

(Signature of Investigator) (Date)

Phone Number

Appendix E

Interview Guide

Interview Guide

Demographic data:
Participant I.D. Number _____ Age (in years)_____

Education (highest grade attained) _____ Employment/Student status_____

In the initial interview the purpose of the study, the confidential nature of the data, and the informed consent will be addressed. The researcher will advise the participant of the time frame for the interview and allow opportunity for questions prior to starting interview. The interview will begin using a broad question which will enable the researcher to get a complete picture of the participants experience (Morse & Field, 1995).

Interview questions to initiate the interview:

Can you tell me about a time when you made a major decision in your life?
What are some of the things that remind you to take care of your health?
Have you ever had a cervical screening test for cancer (Pap test)?

If yes,

Can you tell me about when you first decided to go for a Pap test? Further prompts....What prompted you to make the decision to go for a pap test? When did you first hear about Pap tests? From whom?

Looking back on your experiences with this screening test, tell me what comes to your mind?
Tell me about some of your experiences when you go for a Pap test.
Why or why not do you think it is important to go for a pap test?

If No,

Let's talk about women's health in general.....What are some of your thoughts?
Can you tell me what you know about Pap tests?
Has anyone ever suggested to you that you should have a Pap test?

At the end of the interview:
Are there any comments or thoughts you would like to share with me before we finish the interview?
Is there anything you would like to add that I haven't asked you about?

Other probes that would be used throughout the interview, depending on the response, would be:

Tell me more about that
How do you mean that?
Anything else?

Appendix F

Approval Letter from Human Investigation Committee

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

January 13, 2000

TO: **Ms. Heather Taylor**

FROM: Dr. F. Moody-Corbett, Assistant Dean
Research & Graduate Studies (Medicine)

SUBJECT: Application to the Human Investigation Committee - #99.179

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled "**How Young Women Make Decisions About Cervical Screening**".

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

For a hospital-based study, it is **your responsibility to seek necessary approval from the Health Care Corporation of St. John's**.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

F. Moody-Corbett, PhD
Assistant Dean

cc: Dr. K.M.W. Keough, Vice-President (Research)
Dr. R. Williams, Vice-President, Medical Services, HCC
Dr. M. Laryea, Supervisor