

Women's Wellness:
An Integrative Literature Review and Evaluation Proposal

by

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BScN, University of Victoria, 1986

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Abstract

This paper describes a women's reproductive screening program in a small, rural and remote area of northwestern BC. The Northern Health Authority, in order to provide better care for women in the north, began nurse-run clinical breast examination and cervical screening programs in 2004 to provide women with increased opportunity for preventive health care. An integrative literature review was conducted and provides the foundation for a proposed pilot project to evaluate this women's health program. This proposed qualitative evaluation includes individual interviews to understand the problem and its significance to the women of the Northwest.

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Chapter 1: Integrative Literature Review

Introduction and Background

The Northern Health Authority (NHA) is the largest health authority covering about 2/3 of the province. It is a vast geographical area covering 588,000 sq. km. with a population of approximately 300,000 people (BC Statistics, 2006b). The NHA has the lowest population density per square kilometer (km) of any other Health area (BC Cancer Agency & Northern Health, 2005). The community of Kitimat is nestled among the Coastal Mountains at the mouth of the Kitimat River and at the head of the Douglas Channel 640 km directly north of Vancouver. Due to the mountainous and coastal terrain, there is no direct road connecting Kitimat with Vancouver. Vehicular travel from Kitimat to Vancouver is through Prince George making the one way driving time to Vancouver 18 hours. Kitimat is a rural and remote area of British Columbia.

The population of Kitimat is 10,285 people (Statistics Canada, 2001) with 3,465 women between the ages of 20 and 64 years with 1,375 of them single women. Women are aging in our community with more women represented in the 45-64 age groups than ever before (Statistics Canada, 2001). High school diplomas are held by only 39.2% of women aged 45-64 years (Statistics Canada, 2001). One fifth of the women of Kitimat were born in another country and immigrated to Canada prior to 1991 (Statistics Canada, 2001). Of these women many did not speak English upon arrival in Kitimat and some continue to have difficulty expressing themselves in English in verbal or oral communication. According to Statistics Canada in 2001, there were 2190 women employed in such areas as business, finance, sales, service and administrative

occupations. Financially, the average income level of women in Kitimat is approximately \$23,000 compared to the male average income level of \$54,000 (Statistics Canada, 2001).

First Nations or Metis people comprise about 15% of the population in the NHA (BC Statistics, 2006a). The Kitimaat Village, a First Nation's reservation located approximately 20 minutes from the town of Kitimat, has a population of 511 people with 540 Aboriginal people living off reserve in the town of Kitimat (Statistics Canada, 2001). Women of Kitimaat Village also have limited education and experience a lower income level. The Village is currently in the process of acquiring responsibility for their healthcare. As there is currently no public health nurse employed in the Village, Public Health Nurses from the Kitimat Health Unit provide health promotion and disease prevention services to people of Kitimaat Village.

There are many ethnic groups represented in the town of Kitimat. These include but are not limited to Portuguese and Indo-Canadian people (City of Kitimat, December 21, 2005). The diversity of cultures and specifically the diversity of values and beliefs about health make it essential to gather input for these groups when engaging in health promotion and disease prevention programs.

The Problem and its Significance

The Provincial Health Services Authority (PHSA) which includes BC Women's, the BC Cancer Agency, and the BC Centre for Disease Control, and the Northern Health Authority (NHA) received funding from the Ministry of Health Services to develop a Primary Health Care (PHC) initiative aimed at enhancing women's access to breast and cervical screening. This initiative provided the opportunity to expand PHC into areas of the NHA where there is currently little or no access to screening services. It also provided

the opportunity for discussion about women's general reproductive health including sexually transmitted infection (STI) testing and contraceptive advice. The plan called for the use of existing nursing services in communities in order to provide this care (Anderson, 2003). The community of Kitimat was chosen for this initiative as there was an existing nurse-run contraceptive clinic operating out of the Health Unit. This PHC program would augment the role of the nurse and provide enhanced reproductive care to the women of Kitimat and Kitamaat Village. Women are encouraged to have cervical screening, clinical breast examination and/or mammography done regularly regardless whether it is done by public health nurses or their family practitioners. This PHC program would supplement the current system giving women a choice in their health care.

One would expect the number of cervical and endometrial cancers to be decreasing as BC has had a provincial cervical screening program in place since 1949. However, in spite of a provincial program, many women choose not to have a Pap test or other cervical testing. Cancer is a leading cause of illness and death in Canada. In 2004 in Canada, it was estimated that 1350 women would be diagnosed with cervical cancer and 410 women would die as a result. As well, 2300 women would be diagnosed with ovarian cancer and 1550 would die (National Cancer Institute of Canada, 2004). In 2001 in BC, 138 women were diagnosed with cervical cancer and 44 women died (BC Cancer Agency & Northern Health, 2005). According to the BC Cancer Agency and Northern Health (2005), in the Northern Health Authority 11 women in 2000 were diagnosed with and 5 women died from cervical cancer.

The incidence of breast cancer also continues to be of concern for women. In 2005, 21,600 women will be diagnosed with breast cancer and 5300 will die from it. This is an average of 415 women diagnosed with breast cancer each week. One hundred and two women will die from breast cancer each week (BC Cancer Agency & Northern Health, 2005). The rate of breast cancer is higher in the Northwest with the rate of 121.3 per 100,000 from 1999-2003 compared to the BC total of 105.1 per 100,000 (BC Cancer Agency & Northern Health, 2005). The five year survival rates for women diagnosed with breast cancer are poorer for women in the Northern Health Authority as compared to women who live in other Health Authorities in BC (BC Cancer Agency & Northern Health, 2005).

Statement of the Problem

Women in Northern BC fall short of the provincial average for breast and cervical screening. For a screening program to have optimal effect on death rates, screening of 70% of women is needed (BC Cancer Agency & Northern Health, 2005). The rate of cervical screening in the North is 190.3/1000 women compared to the provincial rate of 205/1000 women age 20-69. For every 1500 Pap smears that are done, one cancer is prevented (BC Cancer Agency & Northern Health, 2005).

The provincial participation average for screening mammography is 47.1%. The participation rate for the Northwest is 33.5%, considerably lower than for the province of BC (BC Cancer Agency & Northern Health, 2005). Women in Northwest BC have lower rates of participation in mammography and cervical screening compared to women in the province of BC. Obviously there are reasons why women are not using either screening

procedure regularly. Exploring these barriers is essential to health promotion and prevention work with women in the North.

Purpose of the Proposed Project

The purpose of this project is to ascertain what invites women and/or prevents women from participating in reproductive health screening. Reproductive health screening includes clinical breast examinations, screening for sexually transmitted infections and Pap smears. An integrative literature review has been conducted and this literature review will then be used to propose a qualitative evaluation with the ultimate goal being to enhance reproductive health promotion and prevention programs for the city of Kitimat and Kitimaat Village. This proposed process evaluation will be used as a pilot study to not only increase women's screening activities but to illuminate current practice and assess the impact or change needed in nursing practice.

Context and Assumptions

Our Health Unit is currently implementing a Women's Wellness Clinic to offer cervical screening, clinical breast exams and referral for mammography for women in the community. Since 2000, public health nurses in Kitimat have offered access to education and affordable birth control for women. Now as part of a Primary Health Care initiative aimed at increasing the rates of screening for women, this role has expanded to include breast and cervical screening. In order to provide quality health care through continued program planning and implementation, it is essential to hear about women's experiences with clinical breast examinations, and/or cervical screening in our community.

I have chosen this topic as I believe that it is important to understand women's perceptions of these types of procedures. In my experience as a community nurse, I have

found that women base their decision to access reproductive screening depending on their own and their family's health history, their past experiences with the health care system, and the relationship they have developed with their health care practitioner.

Routine screening is one of the taken-for-granted health rituals in Canada. Mammography and cervical screening are two types of preventive screening in which many women participate in British Columbia. What are my biases and prejudices regarding these types of screening? I believe that every woman should participate in all preventive screening to enhance her health. I also believe that every woman should have choice about who provides the screening and where the screening takes place. I expect women to be treated with dignity and with respect, that women be treated as equal partners in their care with sharing and understanding of personal health information. Although I expect this collaborative approach towards women from all health care workers, I believe that it does not always happen. Through my work as a public health nurse in northwestern BC, I have heard women share stories regarding their reproductive health care. What I know makes a difference is hearing from women about things that worked well for them and the things that we, as health care providers could improve upon.

As a woman and a nurse, especially one working in health promotion and prevention, I am situated within a system of primary and secondary prevention. Shamansky and Clausen (1980) and Stanhope and Lancaster (1992) describe primary prevention as it is applied to a "generally healthy population" (Shamansky, 1980, p. 106). This term describes a level of prevention that precedes any symptoms of disease. The purpose is to enhance education, support and resources for people to maintain this level

of healthy functioning. For example, primary prevention activities for women could include educational sessions to promote breast self examinations. Secondary prevention, on the other hand, describes a level of prevention aimed at people who are exhibiting signs of disease (Stanhope & Lancaster, 1992). It includes early diagnosis and treatment to change the course of the disease process. The purpose of this level of prevention is to assist the person to return to a stable health state (Stanhope & Lancaster, 1992). For instance, cervical screening activities fall within the secondary prevention level of care.

Because I strongly believe in health promotion and prevention, it is sometimes difficult for me to think that others do not share this priority of care. I believe that women who are immigrants, or who are First Nations may view screening in a different way than I do. I believe that their understanding of their medical experiences is situated within their culture. The importance of history in their experiences is vital to the understanding of their concerns. Their own history and the history of their family's care will impact their experiences and understandings of those experiences. (Audi as cited in McDonald, 2005).

Through the development of this project, I expect to come alongside women in their views for holistic care. I believe that in order to 'wander with' (Kvale, 1996) these women, I need to be able to relate to the phenomenon being investigated. I am a nurse providing care and I am also situated as a client receiving care. I have also had my own experiences of having mammograms and Pap smears. These experiences will impact my perceptions and possible understandings of others' experiences of screening. I need to be aware of my biases and phrase my questions or comments in relation to my experiences and prejudices. I also need to critically examine both the verbal and non verbal cues

expressed by women and I must be aware of my own views and be able to challenge those views.

Conceptual Framework

This project is founded upon the following concepts which together, provide the integrative literature review: community, Primary Health Care, health promotion, embodiment, illness and disease, health and healing, and participation. Each concept will be briefly defined and described in relation to women's participation in cervical and breast cancer screening.

Community

The definition of community varies widely throughout community health literature. According to Stanhope and Lancaster (1992), the community is seen as client, and as a context for community nursing practice. Sheilds and Lindsey (1998), in addition, describe community as a resource and as a relational experience. To view the community as client, the PHN sees the community as a whole. The role of the nurse is to assess the entire health of the community and this view is often seen through epidemiological data (e.g. rates of breast and cervical cancer). McKnight and Van Dover (1994) write that the focus of care is on the "health issues *of* the community" instead of the "health issues *in* the community" (p. 13) (italics added).

The community as context and the community as a resource view the place of care or the environment where a person lives. In this case, the client is seen as a person who lives with a family or group and resides within a specific community setting. Using the definition of the community as resource includes the quality of everyday life where the community environment is dynamic, not static. The accessibility of services is an

important concept within this definition as the accessibility of resources has a direct bearing on the health and welfare of its people. In this situation, the integration of services and reducing barriers to care are important features to consider (e.g. reducing physical barriers to care, transportation concerns). The capacity and strengths of the community are a part of the definition of community as resource (Sheilds & Lindsey, 1998).

Janet McKnight (McKnight & Van Dover, 1994) states that community is about the people's relationships, not just their geography. Sheilds and Lindsey (1998) write that people "experience themselves as being in community... [in] a way of being that permeates throughout people's lives" (p.4). Sheilds and Lindsey (1998) believe that the experience of being in community may "change overtime depending on your age, place of residence and familial relationship" (p. 4). They also state that there are many influences of being in relation in community. Some influences are the socioeconomic and political characteristics of society.

Community is defined as "a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings" (MacQueen et al., 2001, p.1936). McQueen et al. (2001) write that the core elements of community include: locus, sharing, joint action, social ties, and diversity. Other authors including Hillery (1955) and McMillan and Chavis (1986) concur with this reasoning and include in their definition of community: membership, influence, integration and fulfilment of needs and shared emotional connection. For instance, women in Kitimat may describe that they belong to the Sikh or First Nation's community and that they reside in a rural and remote area of BC. These

women share similar health concerns due their gender and location and they also share a sense of diversity in that they may identify as belonging to ethnic groups. However, they collaborate in joint action through engaging in women's wellness activities.

For public health nurses working in this area, we note a sharing of similar values (i.e., wellness) and a number of communities within the community. For instance, in order for the Sikh women to feel included (develop social ties) in the larger community, their values and beliefs, customs and traditions need to be considered. In planning our Women's Wellness Conference for February 2006, we wanted to meet with the Sikh women to learn about their values and beliefs regarding health. It was essential that we entered this community in a respectful way. Therefore, in order to gain a deeper understanding of their customs and beliefs, we initially met with the men of the Temple. Once the men understood our reason for wanting to engage with the women, the women were encouraged to meet with us. By following their traditional ways of entering their group, the women could be included in their health care. Also, the food for the Conference meal was reviewed by the women and was noted to be inclusive of their diet. Although to us it seemed like a small point, to these women, having the appropriate food was considered extremely important. Seeing a female health provider for intimate women's screening procedures was considered to be important to both the women and men. Because of our long-standing public health role within the community and our ability to reach the Sikh community, the women not only attended the Conference, through the relationship they developed with the nurses at the conference, they subsequently attended the clinic for breast and cervical screening. It is, therefore,

imperative to attend to the relational aspects of community in any planning, implementing and evaluation of health promotion events.

Primary Health Care

In 1978, the term Primary Health Care was developed by the World Health Organization (WHO) and the United Nations International Children's Emergency Fund (UNICEF). These two groups represented 24 countries and organizations. The reason for its development was clear: although the rates of communicable diseases were decreasing due to improvements in science and technology, high rates of morbidity and mortality continued due to the impoverished and unsanitary conditions. Morbidity and mortality rates improved with low cost, straightforward local suggestions (Barnes et al., 1995). Out of these discussions, a global health strategy, Primary Health Care (PHC), was developed. "PHC reform promotes an integrated and client-focused approach to the delivery of health services to ensure that Canadians receive the most appropriate care, by the most appropriate providers, in the most appropriate settings" (Kouri & Winquist, 2004, p.1). Therefore, included in health were the social and economic relationships people have in their communities and the "responsibility for health was transferred from the physician, as a healer, to a primary health care worker, as a partner" (Barnes et al., 1995, p. 7).

There are many advantages to change to this system of health care delivery. Health care outcomes and waiting times have improved through a focus on prevention, involvement of the patient and overall coordination and continuity of care. Services are delivered at less cost through more efficient use of resources. According to Kouri and

Winqvist (2004, p. 1-2), “Canada’s goal for its PHC renewal is to develop a sustainable, affordable, accountable and client-focused health care system.”

Although there are many descriptions of PHC in the literature, many authors for example (Abramson & Kark, 1983; Barnes et al., 1995; Hills & Mullett, 2004; MacDonald, 1992; World Health Organization, 1978) believe that PHC includes:

- Accessibility to health care services regardless of where people live, work or play, regardless of the language they speak or their income level;
- Essentiality which includes preventive, promotive, curative and rehabilitative care that communities decide are essential to their health;
- Equity to minimize power imbalances and social determinants of health leading to empowerment of people;
- Community involvement where the community participates in the planning; organizing, implementation and evaluation of culturally appropriate health care services;
- Multidisciplinary/intersectoral collaboration which includes the ability of all health care workers and those from other sectors (e.g. housing, social and political areas), to work together to provide comprehensive services to individuals and communities.

PHC is more than just medical care. It is a reorientation of health care towards the needs of the clients as partners in care including multidisciplinary and intersectoral collaboration providing broad and timely access and empowering clients to become partners in their health care decisions. PHC is not just provided in facilities but it is shared throughout the community in all environments where people live, work and play.

This type of health care is based on a unified and coordinated role for all health care professionals and allied professionals.

Health Promotion

The Ottawa Charter for Health Promotion (WHO, 1986) was innovative in its ability to focus on the socioenvironmental view of health that includes disease prevention, treatment and behavioural issues. "...Empowerment or the capacity to define, analyze, and act on concerns in one's life and living conditions joined treatment and prevention as an essential goal of health promotion" (Labonte as cited in Doane & Varcoe, 2005, p. 29). What does collaboration mean when practicing across differences of race and ethnicity such as seen in our community? Collaborating with women---asking women what type of care they want, how they would like their health care delivered and by who are all important questions that need to be asked. Empowering women to take a stand for their health and the type of health care they want and need, regardless of their color of skin, ethnic background, education level or where or how they live is a substantial part of this type of collaboration (Browne & Fiske, 2001; Johnson, Bottorff, Browne, Grewal, Hilton & Clarke, 2004). Looking at the determinants of health and actively seeking ways with the community members for improvement will bring about positive change in the community.

By seeking the strengths of women and by reaching across the difference to collaborate with women for better health care, it is necessary to look at the concept of "othering." According to Kitzinger and Wilkinson (1996, p. 8), othering is "...intimately related to 'our' notion of whom and what 'we' are. 'We' use Other to define ourselves: 'we' understand ourselves in relation to what we are not". A group is defined not only by

who is in the group but by who is excluded from the group. To reinforce our own identity we push others further away (MacCallum, 2002). This concept of who is the other and who belongs shifts across time and place (Kirkham, 2003). The concept of other is inherent in power relationships. According to Kitzinger and Wilkinson (1996), colonialism created others. Cultural domination of the West led to power imbalances and view of the West in the position of superiority.

The effects of colonization are seen to have many deleterious effects on the health and healing of the First Nation's peoples. Using the lens of cultural safety, the "health and social relations and practices...are shaped by the dominant organizational, institutional and structural conditions" (Smye & Browne, 2002, p. 48). For women, this effect is noted in the paternalistic (women's voices have been silenced as men are seen to be dominant in this society), dependent and medicalized system of health care women receive on Reserve (Browne & Fiske, 2001).

Anderson, Perry, Blue, Browne, Henderson, and Khan, et al. (2003) write that cultural safety is one way to encourage health care providers to reflect what they bring of themselves to the interactions with clients. By pondering our own values and beliefs and our own personal and cultural history, health care providers become aware of ourselves as we are in relation to others. "Cultural safety would prompt us to question our assumptions about women, locate the women's health concern within a structural context, and connect the dynamics of individual encounters to broader social issues" (Browne & Fiske, 2001, p.143).

Influencing patterns of behaviour that lead to positive health outcomes is a significant goal for health programs. For First Nation communities, healing has become

important. In looking at the level of disease, drug and alcohol addiction in their community, elders are asking for leadership through self-government and involvement of their communities in the healing process. For many communities, it is about going back and valuing their roots and their culture, empowering people to their way of life and helping them see choices in their lives. In the First Nation's community, feasts, smudging ceremonies and raising of totem poles are important events that bind people together, connect them, and unify them. Working collaboratively with community members to assist with the spectrum of health care from prevention to disease and illness care, including ways of healing, is an important goal of health promotion (Johnson et al., 2004; Kirkham, 2003; MacCallum, 2002).

For some cultures, religious ceremonies are important parts of their belief systems and their traditions. For some women, the cultural aspect of being a woman is celebrated and welcomed. Health teaching appropriate to the culture and belief system is a vital part of the health promotion work that needs to be done with the women of the community. Paying attention to the signs that would foster healing, the shared sense of what is whole and sound for both the nurse and the woman is essential (Marck, 2000). For nurses to be a part of this type of healing and care, permission to explore the entire experience for both the nurse and the individual woman is needed (Canales, 2000). Being genuine is an important part of this type of care. For women, the evolving process of health promotion is a "balancing act" (McWilliam, Stewart, Brown, Desai, & Coderre, 1996, p. 13) of trying to discover what is and what could be developed in relation to their health and healing. As the environment is constantly changing so do the ways in which we, as health care workers, and the women, as individuals, respond to the needs, wants and aspirations

of each other in the community. Women and their health care workers will draw on their strengths of creativity, determination and wondering curiosity to develop solutions to health concerns and innovative healing strategies (McWilliam et al., 1996).

Embodiment

Embodiment, according to Lawler (1997, p. 31) “is the experience of the lived body.” As well as the determinants of health, people’s view of their body and their self esteem are important factors to consider in looking at concepts of health. Not all people are happy with their body size and shape. Some people hide their bodies from themselves, their family and their caregivers. The secrets they hide—their weight, their wrinkles, their piercings, their scars, their emotions---are all potential sources of embarrassment and vulnerability. They tend to not seek assistance for health issues (physical or emotional issues) until the concerns are far advanced and require more invasive care.

Seeing the body-as-spirit is a common theme within many cultures. Spirituality is not the same as religion but instead it is the part of you that gives meaning and purpose to your life (Doane & Varcoe, 2005). Faith helps shapes people’s goals, hopes and dreams. Faith is something that is nurtured using language and rituals. It is found between us and in us, through our thoughts and feelings, how we perceive events and how these events are recognized and used to further ourselves (Doane & Varcoe, 2005). Seeing the life force wax and wane for people, the change in physical or emotional status can be a sign of an ebbing spirit. For example, loss of spirituality can be found among some people who abuse drugs and alcohol or people who develop other at risk activities such as having multiple sexual partners or entering into prostitution. Their body becomes an

empty shell, without faith to carry on or to find that hidden power to reach their goals and dreams. Instead of looking inside themselves or to others in the community to bolster their waning spirit, their lack of spirituality can lead them to find solace in drugs or alcohol or meaningless relationships (Doane & Varcoe, 2005).

How the body is perceived or the value placed on the body also has an important role to play in the health care of a community. According to Lumby (1997) the body has been seen differently throughout history and culture. In the view of the body-as-shameful, the issues of body image and self esteem create barriers to care for people especially those who have been sexually abused or those who believe that the body needs to be kept hidden. The people, both men and women who have been abused, feel an overwhelming sense of shame, anger, embarrassment and vulnerability to be examined without their clothes. For many, it is not just the physical aspect of removing their clothes but the symbolic view of being naked and defenceless. For instance, the impact of residential school abuse for First Nations' peoples, their family or friends is staggering (Royal Commission on Aboriginal Peoples, 1996). For these women, the thought of attending a health professional, male or female, for any intimate procedure is distressing. The influence of their mother and grandmother in health care activities during this time of their lives leaves some women wondering why health care workers are so concerned about their intimate health (Browne & Fiske, 2001).

When planning health promotion events, the views of the body need to be taken into consideration. For instance, First Nation's women's views of their body may influence their decisions to access care. The impact of colonization has left a broken spirit and a festering sore for the First Nation's people to heal (Browne & Fiske, 2001; Klem, 1998;

Smye & Browne, 2002). Further “healthcare discourses that explicate how culture, history and sociopolitical relations intersect and shape women’s health problems and access to health care” need to occur (Browne & Smye, 2002, p., 38).

Illness and disease

While disease is perhaps most commonly understood from a biomedical perspective, Frank (1991) describes disease as the disconnection of people within their bodies, their life, and their relationships with people (Frank, 1991). The language of disease is objective and the terms are used to indicate a breakdown, either imminent or present. Disease is often related to body measurement while “illness is the experience of living through the disease” (Frank, 1991, p. 12). The concepts of disease and illness are a part of our life. When the body breaks down, so does our life as we know it. Often our response to the illness is the “fear and frustration of being inside a body that is breaking down” (Frank, 1991, p. 12). Putting the pieces of our lives back together can be a daunting task. Many pieces of the puzzle have changed shape and the fit is now different. One cannot measure the hopes and dreams, failures and disappointments of life (Frank, 1991). How we feel about our changed body is a part of living with the illness or disease. Healing is necessary to mend the mind-body-spirit connection.

Health and healing

The definition of health varies widely across populations. The Ottawa Charter (WHO, 1986) says “that health is more than the absence of disease; it is the total physical, psychological, and social well-being, and is a resource for everyday living.” Labonte (1993) in Doane and Varcoe (2005), write that there are three perspectives of health. The first perspective is the medical model that looks at the ‘absence of disease or

infirmity.’ Using this definition the nurse’s role is one of prevention of problems or treatment of disease. For instance, public health nurses provide treatment of sexually transmitted infections such as Chlamydia and the health teaching of safer sex by abstaining or using condoms during sexual activity.

The second perspective is the behavioural model which includes the well-being of people. Using this model, public health nurses provide cervical screening and breast examination for women and discuss possible behaviours changes (i.e. smoking cessation, limiting the number of sexual partners) related to their sexual health. This model includes primary and secondary prevention and is based on changing behaviours or modifying lifestyle to assist people to increased health. This type of care aims to decrease disease and increase well-being.

The third perspective is the socioenvironmental model, which includes the first two perspectives of medical and behavioural models and also incorporates the sociological and environmental aspects of health (Labonte, 1993). In this case, health is a “resource for living; the individual’s ability to realize aspirations, satisfy needs, and respond positively to the environment” (WHO, 1986). For many populations, this perspective is much more inclusive of their health. For some people, it is not the lack of knowledge or the ability to change their behaviour that is crucial to their well-being. It is those things in life that influence their ability to be healthy---the determinants of health. Such things as food, water, shelter, finances, and education are necessary to help achieve health; it is this lack of adequate food, water, shelter, and life skills that interfere with the attainment of their health goals. This interconnectivity of the social and environmental concerns along with the individual’s behaviour influences their health status (Browne & Smye, 2002). In

looking at levels of health among women, providing education about disease, screening for disease and assisting women to change their behaviour is only one part of the puzzle. If women have low self esteem, poor living conditions, no money, poor education, and see no future for themselves or their families, they are more likely to continue their high risk behaviours (Browne & Smye, 2002).

According to the Collaborative Nursing Program Philosophy (as cited in (McCormick, 2003, p.113), “healing has a relational quality and emerges from the interaction between healer and client.” Healing means the harmony of mind-body-spirit. It is the connection, the relationships, the wholeness and patterns of people in their life. Quinn (1989) is clear in her writing that curing is designed to eliminate disease whereas healing is about wholeness or health. This process is a dynamic one with many shifts in the relationship between the body’s systems, the person’s connections with people and their community. By focusing on issues that are of importance to women, public health nurses can assist women to begin to take an active role in their health (Browne & Smye, 2002).

Each of the concepts that were described previously all have an impact on women’s participation in screening. The sense of community, their understanding of health and wellness and the sense of control in their lives, the women’s view of her body and the impact of a potential illness or disease on the woman and her family are all factors to be considered in their ability to engage in health promotive or preventive care. What is the meaning of these concepts in relation to access and participation in screening activities?

Participation in screening

As a nurse working in health promotion and prevention, I see a difference between access and participation in screening activities. Breast and cervical screening has been available to women for many decades. According to the Northern Cancer Control Strategy (BC Cancer Agency & Northern Health, 2005) and the report of Lee, Parsons and Gentleman (1998), the incidence of breast and cervical cancer continues to rise despite efforts to decrease it. Why is this so?

There are many factors that contribute to higher rates of cancer in the north. As it was stated earlier, the NHA has a First Nation population of approximately 15% (BC Statistics, 2006a). First Nation women, according to Steven et al. (2004, p. 306), “in general have a higher incidence of cervical cancer...[and] native women in BC in particular have a 4-6 times higher mortality rate from cancer of the cervix that women in the general population. These women used screening irregularly and less frequently than other women in British Columbia.”

Research contends that there are many barriers to screening (Grindel, Brown, Caplan, & Blumenthal, 2004; Gulitz, Bustillo-Hernandez, & Kent, 1998; and Katapodi, Facione, Miaskowski, Dodd, & Waters, 2002). Some of the barriers that contribute to lower levels of screening include: low income and low education level, cultural issues of privacy, modesty, lack of knowledge about breast cancer risk, lack of regular health care, fear of finding cancer, residents of rural settings, language barriers and being single or having non-supportive spouses. As a nurse practicing in a rural and remote location, I see women with lower income who may also exhibit cultural issues of privacy, modesty and they may experience language barriers or lack the education necessary to understand the

importance of screening procedures. Finding ways to overcome these barriers is crucial if increased screening is to happen.

Smye and Browne (2002), Polaschek (1998), and Anderson (2003) explore many examples of barriers to care that are related to the caregivers' attitudes, healthcare policies and social and economic structures that support the dominant practices. Cultural safety, defined by Anderson et al. (2003, p. 198) includes those "actions that will recognize and respect the cultural identity of these women, taking into consideration their needs and rights as a diverse population is crucial in order to break down these barriers...nurses need to reflect on their own personal and cultural history and the values and beliefs they bring to their interaction with patients..." Many authors including Anderson (2004), Browne and Smye (2002), Polaschek (1998), Smye and Browne (2002), and Taylor (1999) write that cultural safety is paramount if the health of marginalized groups is to be improved.

Sutherns, McPhedran, and Haworth-Brockman (2004) cite the impact of poor socioeconomic status on the health of women. One fifth of Canadian women live in a rural area. Women living in rural and remote areas of Canada face a number of health issues including cancer. According to the Sutherns et al. (2004), many women living in rural and remote Canada tend to work less, have a lower income than the urban women, and have less income security. Rural women tend to have more children and therefore more family responsibilities, and have a higher risk of dying from many causes including cancer. Lack of education and money make medical appointments difficult for these women. These women tend to have to travel longer distances for medical care and often transportation is difficult to arrange due to finances or family commitments. Women are

often the caregiver for their family (including extended family) whose needs are often put aside until she has the time, energy or ability to deal with them. If it is too late to provide the care for her, her illness, and possible death, has a devastating impact on her family.

The report of Sutherns et al., (2004), proposes that women in rural and remote areas and those who are marginalized in the population are at increased risk of not having had a Pap smear. Likewise, Lee et al. (1998, p. 9), write that the “characteristics of women with high odds of never having had a Pap test are: being single, being a resident of Quebec, having immigrated to Canada, having less than a secondary education, and not being in the highest income group, and having had no sex partners in the previous year.”

This places many of the women of Kitimat and Kitamaat Village in the group with high odds for never having had a Pap smear or breast screening. Many are single, have immigrated to Kitimat (many of the older women came with their husbands from other countries to Kitimat in the early years of the development of the town), have less than a secondary education, and have a limited income. Factors influencing women’s health in Kitimat/Kitamaat Village could be geographic isolation, poor weather, lack of transportation, and lack of education or language barriers. Thus, the towns of Kitimat and Kitamaat Village are truly representative of a rural and remote focus in health care due to their geographic location and poor socioeconomic status.

Other factors such as an aging population, tobacco use and overweight or obese women coupled with lower screening rates contribute to increasing rates of cancer. Presently, the population of the north is relatively young but by 2015, we will see an increase in the proportion of seniors (Statistics Canada, 2001). In the next 10 years the

NHA expects to see an increase in the number of new cancer diagnoses mostly due to an aging population. Breast and ovarian cancers are among 12 cancers that the NHA expects to see increased. If the present direction continues, the Northern Health Authority expects to see 202 new breast cancers and 34 endometrial cancers diagnosed by 2015 (BC Cancer Agency & Northern Health, 2005).

Tobacco is a known risk factor in the development of a variety of cancers including cancer of the breast, cervix and uterus. The number of tobacco smokers in northern BC is high with approximately 32% of the population currently smoking (BC Cancer Agency & Northern Health, 2005). Other risk factors include the incidence of Human Papillomavirus (HPV). Having this virus increases the risk of cervical and other genital cancers (BC Centre for Disease Control, 2004). What is known is that cellular changes are found with pap smears and if caught early, treatment can begin.

According to BC Healthy Living Alliance (Krueger & Associates, Inc., 2004) 43.9% of women in northwestern BC are overweight and obese as compared to 33.2% of women in BC. Obese women when compared to non-obese women are at an increased risk of developing endometrial, cervical, and postmenopausal breast cancer (Fontaine, Heo, & Allison, 2001). Fontaine et al. (2001), write that obese women are more likely to not attend for breast, mammography or cervical screening. Many reasons are speculated for women's lack of attendance for screening and more research is needed in this area.

From the literature it is clear that one must consider the history, attitudes, practices and cultural beliefs of populations when developing strategies to address barriers to effective breast and cervical screening. Developing local knowledge, specifically related to the barriers to participation in care, is essential to assist the nurse to

develop an in-depth understanding of women's health concerns. Understanding the experience of women living in rural and remote areas will assist the nurse in providing education, screening and support using health promotion and screening activities. This proposed project will address the gap of knowledge regarding women's experiences of reproductive health screening in a rural and remote area of the province.

Chapter 2 Evaluation Proposal

Introduction

Within this chapter I will propose a qualitative interpretive evaluation that could be conducted to further understand the experience of women of Kitimat and Kitamaat Village with the goal of increasing accessibility of screening services. The proposed pilot study is one way that voice of this group of women could be heard. Using a qualitative methodology the researcher will explore women's perceptions of the barriers to accessing breast cancer and cervical screening. The purpose of using a key informant evaluation is not only to increase women's screening activities but to illuminate current practice and assess the impact or change needed in nursing practice. Using feedback from the women to improve practice is necessary to adequately address the health needs of this population. Continually questioning and adjusting our practice through research is an important part of professional growth and development.

According to Patton (2002), this type of qualitative inquiry is appropriate for studying process for many reasons. Some of these reasons for using qualitative inquiry are: that the process is typically different for different people and their experiences need to be captured using their own words; it will detail how the people engage with each other; no single rating scale can summarize the fluid and dynamic shift in their experiences and the perceptions of the participants are the key process consideration. Understanding how the internal dynamics of a program works is imperative to assist with the understanding of the people's experience that make the program what it is and how to use this information to ascertain the strengths and weakness of the program from the perspective of the workers and the participants. It is through this type of evaluation that the strengths of the program will be highlighted as well as those areas needing revision. As this is a pilot study, it is imperative that this type of information be

gathered for continuation of funding and replication of this program in other sites across the north.

Interpretive research seeks patterns and themes that evolve into new ways of looking at the phenomena of interest. Jardine (1998) discusses dwelling on incidents, taking the time to really think about what was said, paring down the information that has been collected to its bare essence, to the point that causes people to nod and smile when hearing the comments. It is at this point that the fine tuning needed to ascertain that you have indeed arrived at the moment of understanding (Heidegger as cited in Johnson, 2000). Using critical thinking or continual questioning of assumptions, observations, experiences and learning is one way to further our understanding. By identifying and challenging these assumptions which underlie our beliefs, ideas, values and actions that we take for granted, we challenge ourselves to look at our perceptions, our understandings and interpretations in a different way (Ceci, 2000; Johnson, 2000; Kvale, 1996). Thus, the taken-for-granted-ness of breast or cervical screening is being challenged and this thread will weave its way through hermeneutic inquiry (McDonald, 2005).

Using language through narratives to further this understanding helps elucidate deeper meaning (Kvale, 1996). Clarification of thoughts, experiences with the person is important as there are many interpretations of an experience and thus many ways to understand the behaviour. As Kvale (1996) suggests, the researcher needs to be well versed about the interview topic, knowledgeable about the types of methodologies available and understand how knowledge is produced through conversations. This “wandering together” (Kvale, 1996) along with the researcher’s personal experience and perception allow the researcher to discover the interpretation and understanding of the experience and to “develop methods and procedures for further investigation and analysis...the self of the researcher is present throughout the

process and, while understanding the phenomenon with increasing depth, the researcher also experiences growing self-awareness and self- knowledge” (Patton, 2001, p. 107).

Sample

The target group will be female stakeholders from the First Nation, Portuguese and Indo-Canadian population between the ages of 19 and 69 years in Kitimat and/or Kitamaat Village. The purpose of seeking key informants (Patton, 2001) is to hear the insights of various groups of people within the population who are especially knowledgeable about the phenomena under study. These people can provide useful information needed to help the researcher understand the topic (Patton, 2001). The people in these groups or sub-groups might otherwise remain silent. This population is of interest because as key stakeholders, these women will provide insights into the barriers and promoters of breast examination, mammography and cervical screening services for women. The town of Kitimat and Kitamaat Village are multi-ethnic with a variety of different cultures present including but not limited to Portuguese and Indo-Canadian people. Fifteen percent of the population are of First Nation descent (BC Statistics, 2006a). First Nation women have a much higher rate of cervical cancer and the mortality rate is much higher for this group (Steven et al., 2004).

Selected interviewing techniques will be used to identify key informants in the community. Key informants are people who are particularly knowledgeable about cervical screening and breast examinations and who are willing to share their knowledge and insights to help the researcher understand the experiences of women. These are also people who might otherwise remain silent. The target group will be female key stakeholders from the First Nation, Portuguese and Indo-Canadian population between the ages of 19 years and 69 years in Kitimat and/or Kitamaat Village. This population is of interest because as key-stakeholders,

these women will provide insights into the barriers/promoters of breast examination/cervical screening service for women in our community. Kitimat is a multi-ethnic community and programs need to reflect the diverse needs of the women. Fifteen percent of the population of the Northwest is from the First Nation's community. First Nation women have higher rates of cervical cancer and experience lower rates of cervical screening. Due to the large First Nation population and the high rate of cervical cancer within First Nation's communities, the expectation to interview at least 2 key informants in this group of people is reasonable. This discussion may be well received within the community following the Women's Wellness conference held in February 2006. Many women in town attended the conference and much discussion of women's health issues has ensued. Interviews will be used to open a space in conversation for women to explore and express themselves through narratives to illuminate their experience of breast examination and/or cervical screening in their lives (Kvale, 1996; McIntyre, Anderson, & McDonald, 2001).

A third party recruiter will be used to assist with the recruitment of women to prevent any real or perceived possibility of "power over" occurring between the researcher and the women. A sample script for use by the third party recruiter is found in Appendix A. Initial contact will be made in person or by phone with the third party recruiter to discuss the purpose of the research, expectations of the participant (including audio-taping) and expectations of the researcher. The script would contain as much information as needed including the purpose, risk and benefits of the study for the woman to consider her involvement in the research. Once the woman agrees to the interview, the researcher would contact the women and arrange for a time to discuss the interview process including the informed consent. Consent may be required from the First Nation Community. See Appendix B for a sample letter that will be sent to the First

Nation's Executive Director of Health Programs. It is expected that a total of five women will be interviewed with at least two of them from the First Nation's community. Other populations to be interviewed are the Portuguese and Indo-Canadian groups.

An audio-taped interview will be conducted to elicit information regarding women's experiences of breast and cervical screening in a rural and remote setting. See Appendix C for sample questions. The interviews are expected to take approximately 2-3 hours and will be conducted in a private office at the Kitimat Health Unit or in the Kitamaat Village Clinic or in the person's home. Inconveniences to the women may be the 2-3 hours of her personal time as well as the possibility of child care or transportation.

Rigour and reflexivity

Accounting for the integrity of any project is important in all types of research but especially important in qualitative research. After reading Koch and Harrington (1998) I found their suggestion of accountability through reflexivity to be sound. Focusing or reflecting back on the entire research project including the reasons the researcher engaged in the phenomena, the researcher's pre-understandings, beliefs, prejudices and assumptions, the selection of participants, the elucidation of the ethical issues and the interpretation of transcripts leads the researcher and the reader to the interpretation of the experiences. Because the hermeneutic circle is never-ending, I expect the reader to follow the path through the research process, read and reflect on my analysis and continue with his/her own interpretations.

The researcher needs to be aware of any possible power-over relationships in the community if she is currently working in health care. If any potential power-over relationships exist, a third party will need to be used to recruit any women for interviewing. Use of a third party recruiter will ensure women can exercise their right to decline to participate in the study. The researcher must not currently be providing service to the women and /or her family and there needs to be a choice of another care giver should the need arise. The decision to participate will not affect the access or level of service experienced by the women.

The researcher also needs to critically examine each step of the process. Ethical integrity is tangled within this reflexivity. The selection of the participants, the types of questions asked and the maintenance of the power imbalances are important to describe. For example, interviewing women regarding intimate screening procedures suggests that I need to be careful with the types of questions I ask and how I phrase those questions. Because of the sensitive nature of my topic, I needed to be clear with the women I interview that they can share as much or as little as they wish. The issue of informed consent will be addressed as an ongoing agreement between us.

Ethical considerations

This qualitative research conforms to the University of Victoria Ethical Review Board requirements for using human subjects in research. If this evaluation research was to be conducted, ethical approval would be sought and obtained from the NHA prior to engaging in the study. Following contact with the third party recruiter and with the woman's permission, I would contact them by phone to set up the interview. Interviews will be arranged at a place and time convenient to the women involved with the interviews. The place will be comfortable and private. Ensuring the confidentiality when

using their home would be discussed. Further discussion of the audio taping of the conversation would take place prior to starting the interview.

According to Kvale (1996), there are several important ethical issues to be discussed. Firstly the issue of informed consent is paramount in the discussions with the participants. The word “informed” means exactly that—the participants need to be adequately informed of the purpose and the structure as well as any risks or benefits of the study to them. The participant needs to understand that their participation is voluntary and that they can withdraw from the study at any time and have their information destroyed. The importance of describing the full nature of the study including the design and purpose is critical. The balance in describing the study to its fullest potential without impacting the study can be difficult. In a qualitative study, the types of questions are not always known in advance. In a situation where the individual could need further follow up, referral will occur following the interview. Each participant will be asked to read and sign a consent for participating in the study. The consent will also be read to them to ensure they understand it. The participant will be given a copy of the consent for their records and they will be made aware of the fact that they can withdraw from the study at any time without penalty. As each woman for this study will be of legal age, they will be able to legally give consent.

Confidentiality is crucial. The protection of the participant’s names and circumstances is of paramount importance in a small town. Anonymity is very important for the study participants, again because of a small town. Confidentiality of records is essential. All interviews will be recorded on tapes and the tapes and transcription of them will be locked in my desk. Once the transcriptions of the interviews are complete, the

tapes will be destroyed. The transcriptions and analysis will be kept on a password protected computer in a locked office.

Consequences of the study need to be addressed according to Kvale (1996). The purpose of the study is to promote the common good and a risk benefit analysis is an important part of this process. For the researcher, it is important to reflect on the possible outcomes of the study for the participant as well as the group of people that they represent. The participants' sometimes feel that the undivided attention from the interviewer has positive benefits to them (they were listened to with undivided attention) but it could also have negative outcomes for them. Occasionally participants disclose experiences to the researcher that they may later regret. The researcher needs to be aware of this and respect the boundaries of the participant with careful and considerate questioning.

Kvale (1996) writes that the beneficial consequences of the study are the outcomes of the women's views that will help the writer in evaluating a Women's Wellness Clinic. In this instance, using women's experiences to inform services for women will be beneficial. The women's experiences, their choice in caregivers, and the impact of the women's experiences of screening would be important factors to consider in developing the clinic. The other possible benefit could be the time the interviewer spent with the women would be seen by the women as cathartic. Their views, their thoughts, feelings and experiences would be discussed and heard by someone in the health care field. For many women, this would be the first time someone has actually listened to their story. For others, they may feel that by participating in the study they will be assisting to improve the quality of care received by women. The study could

contribute to enhancing the human condition by listening to women's voices and using that information to actively impact the care and design of a women's clinic. The contributions of the participants will be both for them and for the group of women as a whole. It will also assist to inform the general knowledge of the topic.

Concerns related to the negative consequences for participating in the study are managing any feelings that come out of the discussions. The possibility of referral to local mental health clinicians to discuss these concerns will be offered as part of the informed consent process.

This research will look at the barriers and or enhancers for women in attending for breast and/or cervical screening. Engaging in discussions with women who are identified as key informants is an important part of this study.

Conclusion

This paper describes an integrative literature review and a pilot project to evaluate a women's preventive health clinic in rural and remote BC. In order to accomplish this research there are many steps to consider. (See figure 1). The first step is to identify the problem under study. This paper has outlined the problem, the significance of this problem as well as a comprehensive literature review about women's reproductive health. The next step is to begin discussion of this proposal within the organization to advocate for the evaluation of this service. The proposed evaluation proposal will be used to act as a catalyst for discussion among colleagues and senior management, may be one of the ways to engage Northern Health Authority (NHA) in this evaluation. Also, perhaps creating a discussion forum among women in the community is another way to accomplish this goal. Using the momentum of the

Women's Wellness Conference may be a way to foster continued discussion of this topic in the community. The last step will be to co-create a shared understanding of the importance of this evaluation in overall program evaluation by the NHA to secure support and funding. By a hermeneutic process whereby theory informs practice informs theory, the lived experience of women undergoing preventive reproductive health screening will be heard, programs enhanced and modified to empower women to take charge of their health. The burden of disease will be lowered and the health of the community will be improved.

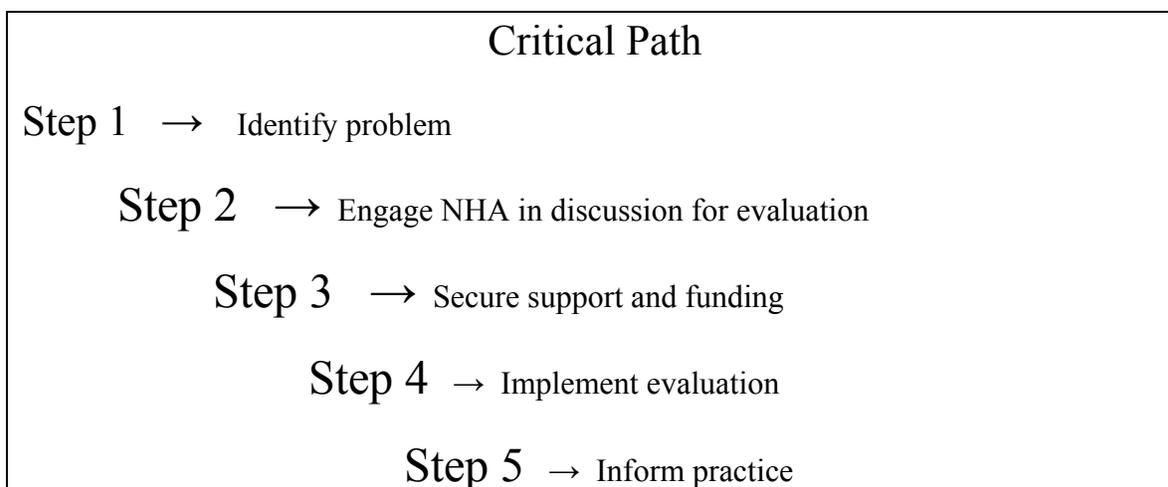


Figure 1: Elements in the critical path for evaluation of program

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Appendix A

Sample Script

Edna McLellan is a registered nurse who is currently a graduate student studying for her Masters of Nursing: Advanced Practice Leadership through the University of Victoria. As part of her studies she is required to conduct research in an area of interest.

This research is being conducted under the supervision of Dr. Laurene Shields. You may contact her supervisor at 250-721-6467.

Purpose and Objectives

The purpose of this research project is to interview women to hear their experiences of breast examination and/or cervical screening. By examining these experiences, as the researcher, she can consider some of the assumptions and beliefs that we take for granted regarding this type of screening and how these assumptions and beliefs impact the service that is provided for women. Looking at what enhances service or erects barriers to service is an important aspect of program evaluation. The evaluation will serve to identify the barriers and enhancers of care and ways to improve the type and quality of service offered to women in a rural and remote setting.

Importance of this Research

Research of this type is important because the research outcomes will be used in planning future women's health initiatives and improving the quality of care women receive for reproductive screening in our community.

Participants Selection

You are being asked to participate in this study because you are considered to be a key informant. A key informant is someone who is knowledgeable about women's experiences of cervical screening and breast examinations and is willing to share the information with the researcher. Your name was identified through discussion with women in the weeks following the Women's Wellness Conference and Health Fair in Kitimat in February 2006.

What is involved

If you agree to voluntarily participate in this research, your participation will include approximately 2-3 hours of your personal time, a willingness to be audio-taped and share your experiences of breast examination and cervical screening including Pap screening with Edna, the researcher. Your interview will be a private 1:1 interview in a private office either at the Kitimat Health Unit or the Kitimaat Village Health Clinic, if available. You will be asked questions regarding your thoughts and experiences of breast examinations and cervical screening including Pap smears. Some of the questions could be:

- What are the barriers to breast and/or cervical screening for Northern women?
- What barriers do you see that affect women's access to breast/cervical screening?
- What can we do to improve access to breast/cervical screening?
- What could we do to improve access for Pap tests and breast examinations?
- If you visited a public health nurse for your pap test, what was different for you?
- What is your wish list for women's health in the north?

Your participation must be completely voluntary. Would you be interested in talking to Edna to gain further information regarding participating in this study?

Appendix B

Sample letter

Haisla Health Centre
PO Box 1101
Kitimaat Village, BC
V0T 2B0

Dear

I am a graduate student in the department of Nursing at the University of Victoria and a public health nurse in the community of Kitimat. As a graduate student, I am required to conduct research as part of the requirements for a Masters' degree in Nursing: Advanced Practice Leadership. It is being conducted under the supervision of Dr. Laurene Shields, Professor of Nursing, University of Victoria.

I am writing you this letter to request an opportunity to speak with two Haisla women regarding their views of women's breast and cervical screening. I understand that this information is sensitive in nature and the Village Administration like to be aware of anyone speaking to the Haisla people regarding their health. I value the collaborative relationship that we have enjoyed over the past several years and I look forward to a continued association with the Haisla people.

Women in rural and remote settings and especially First Nation's women have higher rates of breast and cervical cancer as compared to other populations. For women in our community this statistic is troubling. We know from the research that women who do not access screening have higher rates of morbidity and mortality from the disease.

Purpose of the study

The purpose of this research project is to conduct individual interviews with 2 women to learn about their experiences of breast and/or cervical screening. I would like to interview those women who are particularly knowledgeable about breast and cervical screening concerns in your community. These women would be able to share their insights into the problem and help me understand the concerns. By examining these experiences, I can consider some of the assumptions and beliefs that are taken for granted regarding this type of screening and how these assumptions and beliefs impact the service that is provided for women. The research will serve to identify the barriers and enhancers of care and ways to improve the type and quality of service offered to women in a rural and remote setting.

Importance of the study

Research of this type is important because the research outcomes will be used in planning future women's health initiatives and improving the quality of care women receive for reproductive screening in our community.

Who will be interviewed

Two women between the ages of 19 years and 69 years with key positions in the community will be sought. The purpose of seeking key informants is to hear about insights from various groups of women who might otherwise remain silent. A key informant is someone who is knowledgeable about women's experiences of breast and cervical screenings and is willing to share the information with me.

Freedom to choose

Due to my position as a public health nurse, I want to ensure that women have the freedom to choose to participate. Therefore, I have arranged for Amy Hagerman to assist me and act as the third party recruiter. Having Amy act in this capacity allow women to freely choose to participate. Initial contact would be through Amy by phone or in person to discuss the purpose of the research and the expectation of the participant and the researcher. This process is needed for the women to gain as much information as they need to consider their involvement in the research. Discussion of the benefits/risks of the research will be shared with the participants to help them determine if they would like to participate in the study.

The next steps

Once a woman voluntarily agrees to participate, I will contact her by phone to arrange the interview. Her participation will include approximately 2-3 hours of personal time, a willingness to be audio taped and share her experiences of breast examination and cervical screening, including Pap screening, with me. The interview will be a private 1:1 interview in a private office either at the woman's home, the Kitimat Health Unit or the Kitimaat Village Health Clinic, if available. The participant will be asked questions regarding her thoughts and experiences of breast examination and cervical screening including Pap smears. Some of the questions could be:

- What are the barriers to breast and/or cervical screening for northern women?
- What would encourage women to come for screening?
- What could we do to improve access for Pap tests and breast examinations?
- If you visited a public health nurse for your Pap test, what was different for you?
- What is your wish list for women's health in the north?

Benefits/risk of participating in the research

The potential benefits for the participants as a result of participating in this research include an increase in knowledge and awareness of the importance of and participation in cervical screening and breast examination procedures. Because of the women's participation in the study and with increased knowledge, they may tell others of the importance of this type of screening. With increased screening the health of women will improve. By assisting with this program evaluation, the types of programs, how they are

planned and implemented may change to reflect the needs of women in our community and lead to improvement in the quality of women's health care.

The potential risk to the women participating in this research is emotional upset. As we will be discussing previous reproductive health screening procedures, this discussion may cause women to feel stressed or anxious especially if this relationship with their previous health care provider or screening procedure did not go well. Also, any discussion of intimate relationships (including breast examinations or Pap smears/cervical screening) may bring memories of previous sexual abuse to the foreground. To prevent or to deal with these risks, discussion of the possibility of this happening and ways to manage thoughts and feelings will occur with the women prior to any interview taking place. I will provide the following phone numbers of local mental health clinicians so that the women could call if they wished assistance with any concerns.

Kitimat Mental Health 632-3181
Northwest Counselling Centre 632-6400

Voluntary participation

Participation in this research must be completely voluntary. If a woman decides to participate, she may withdraw at any time without any consequences or any explanation. If she does withdraw from the study her data will be destroyed and all transcripts of the data and other information shared with the researcher including any analysis will be destroyed.

You may contact me if you have further question by email edna.mclellan@uvic.ca or by phone @ 250-632-2233.

You may also contact my supervisor, Dr. Laurene Sheilds @ 250-721-6467.

Thank you for your consideration of this matter. I look forward to hearing from you at your earliest convenience.

Sincerely,

Edna McLellan RN BScN
69 Charles Street
Kitimat, BC
V8C 2J4

Appendix D

SAMPLE PARTICIPANT CONSENT FORM

Women's Wellness Project

You are invited to participate in a study entitled "Women's Wellness" that is being conducted by Edna McLellan RN.

I am a graduate student in the department of Nursing at the University of Victoria and you may contact me if you have further questions by email edna.mclellan@uvic.ca or by phone @ 250-632-2233.

As a graduate student, I am required to conduct research as part of the requirements for a degree in Nursing: Advanced Practice Leadership. It is being conducted under the supervision of Dr. Laurene Sheilds. You may contact my supervisor at 250-721-6467.

Purpose and Objectives

The purpose of this research project is to interview women to learn about their experiences of breast examination and/or cervical screening. By examining these experiences, as the researcher, I can consider some of the assumptions and beliefs that we take for granted regarding this type of screening and how these assumptions and beliefs impact the service that is provided for women. Looking at what enhances service or erects barriers to service is an important aspect of program evaluation. The evaluation will serve to identify the barriers and enhancers of care and ways to improve the type and quality of service offered to women in a rural and remote setting.

Importance of this Research

Research of this type is important because the research outcomes will be used in planning future women's health initiatives and improving the quality of care women receive for reproductive screening in our community.

Participant Selection

You are being asked to participate in this study because you are considered to be a key informant. A key informant is someone who is knowledgeable about women's experiences of cervical screening and breast examinations and is willing to share the information with the researcher. Your name was identified through discussion with women in the weeks following the Women's Wellness Conference and Health Fair in Kitimat in February 2006.

What is Involved

If you agree to voluntarily participate in this research, your participation will include approximately 2-3 hours of your personal time, a willingness to be audio-taped and share your experiences of breast examination and cervical screening including Pap screening with me as a researcher. Your interview will be a private 1:1 interview in a private office either at the Kitimat Health Unit or the Kitamaat Village Health Clinic, if available. You

will be asked questions regarding your thoughts and experiences of breast examinations and cervical screening including Pap smears. Some of the questions could be:

- What are the barriers to breast and/or cervical screening for Northern women?
- What barriers do you see that affect women's access to breast/cervical screening?
- What could we do to improve access for Pap tests and breast examinations?
- If you visited a public health nurse for your Pap test, what was different for you?
- What is your wish list for women's health in the north?

You may also choose not to answer any of the questions posed by the researcher without penalty.

Inconvenience

Participation in this study may cause some inconvenience to you, including 2-3 hours of personal time for the interview. Child minding or transportation to and from the interview may be inconveniences experienced by you.

Risks

There are some potential risks to you when participating in this research. One risk is the potential for emotional upset. As we will be discussing previous reproductive health (pap tests and breast examinations) screening procedures, this discussion may cause you to feel stressed or anxious especially if this relationship or screening procedure did not go well in the past. Also, any discussion of intimate relationships (including breast examinations or Pap smears/cervical screening) may bring memories of previous sexual abuse to the foreground. To prevent or to deal with these risks the following steps will be taken: discussion of the possibility of this happening and ways to deal with your thoughts and feelings. The following phone numbers are those of local mental health clinicians whom you could call for help with these thoughts or feelings if necessary:

Kitimat Mental Health 250-632-3181
Northwest Counseling Centre: 632- 6400.

Benefits

The potential benefits of your participation in this research include an increased knowledge and awareness of the importance of and participation in cervical screening and breast examination procedures. By virtue of being a key informant, and with this increased knowledge, you may tell others of the importance of this type of screening. With increased screening, the health of women will improve. By assisting with this program evaluation, the types of programs, how they are planned and implemented may change to reflect the needs of women in our community. This will lead to increased knowledge of and improvement in the quality of women's health and health care in our community.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation.

If you do withdraw from the study, your data will be destroyed and all transcripts of the data and other information shared with the researcher including any analysis will be destroyed.

Researcher's Relationship with Participants

As I am a local public health nurse, my position in the community may influence you regarding your decision. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken: I am not currently involved in providing care to you or your family; there is a choice of another care provider for you and your family should you need care; recruitment of you to the study has been done by a third party. Your decision to participate in this study or choice not to participate will not affect your access to or level of services at the Health Unit.

Anonymity

Protecting your anonymity may be limited in a small town where female key informants are recruited for participation in this study. Other women will have suggested your name to me but I will be the only person who knows that you have participated in the study. Although you will have been assigned a number, due to the nature of personal interviews, I will know what you said initially. Once the data is transcribed and presented using number identifiers, your data becomes anonymous. If you are well known to me, certain words or phrases commonly used by you will be difficult for me not to recognize as I review the transcripts. This information will not be shared with anyone other than my committee supervisor who will only know you as a number. A transcription service (one located out of town) will be used to transcribe the interviews and all names and places will be removed.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected as once you are identified and consent to be interviewed, you will be assigned a number for transcription of your information. A confidential office will be used to interview you and all data (audio tapes, transcripts and analysis) will be secured either in a password protected computer in a locked office or in a locked filing cabinet in a locked office. Once the interview is complete, any identifiers such as names and places will be removed. A transcription service (one located out of town) will be used to transcribe the audiotapes. Limits to confidentiality would be regarding legal requirements of reporting child abuse or if you disclosed that you were going to harm yourself or others.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways: a final written report will be offered to the participants; a written submission is required for the Master's Project, and oral submissions to other health professionals at staff inservices. Any identifying material including your name, (which was removed prior to the analysis), will remain confidential throughout this process.

Disposal of Data

Data from this study will be disposed of by December 2007. Audiotapes will be kept in a locked filing cabinet and once transcribed, the audiotapes will be erased. Transcriptions of data will be kept in a locked filing cabinet in a locked office. Any data (including analysis) will be stored in a password protected computer in a locked office. Once the Master's project is complete (including oral defence), all electronic data will be deleted and any paper data will be shredded.

Contacts

Individuals that may be contacted regarding this study include the researcher: Edna McLellan 250-632-2233 or her supervisor Dr. Laurene Sheilds @ 250-721-6467. The third party recruiter is Amy Hagerman and she can be contacted @ 250-279-2691.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4545).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

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Title of Project:

Women's Wellness: An Integrative Literature Review and Evaluation Proposal

Author

Edna McLellan

Signed:
