Cervical Cancer Treatment Policy in Urban Saskatchewan: A Feminist Case Study

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Abstract

Treatment based on biomedical principles has become the normative structure for medical practice in Canada. This model, however, imposes on patients rather than involves them as active agents in care. This feminist case study assesses the extent of a women's health approach within cervical cancer treatment at a cancer clinic in western Canada. It critically examines the rationale for and implementation of the clinic's policies drawing from semi-structured interviews with nine professionals working in cervical cancer treatment as well as from relevant information distributed to patients. Of the nine participants in the study, few were aware of women's health approaches and among those who were, it is apparent that the program does an inadequate job of representing women's needs. The recommendations of this project direct attention towards raising the profile of women's health and incorporating gender-based analysis into the biomedical treatment setting. The research identifies a need to raise the awareness of healthcare professionals who work in the area of women's health by emphasizing the importance of involving women directly in the formation of clinic policies in an attempt to prize experience as much as evidence.

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Introduction

Within the last ten years a direct scientific link has been found between the sexually transmitted infection, human papilloma virus (HPV), and cervical cancer. This link indicates that asymptomatic HPV infections can, and will, ultimately lead to changes in the cells of the cervix which will progress into cancer if not treated (Furumoto & Irahara, 2002). While safe sex and harm reduction programs are working to reduce the overall incidence of all sexually transmitted infections (Gollub, French, Laka, Rogers & Stein, 2001), there are specific protocols for the treatment and prevention of HPV and cervical cancer. This treatment involves pap testing to determine if cell change has occurred on the cervix, and if change is significant, a biopsy is performed to assess the level of change. If the level of cell permeation is beyond a certain stage, surgical measures are initiated to isolate these cells by either cryotherapy (freezing) or laser surgery (burning) (Cervical Cancer in Canada, 1998).

Initial testing for sexually transmitted infection/disease (STI/D) normally takes place at a community clinic or other medical delivery centre which specializes in sexual health and can provide counseling and referral services for women needing further treatment. However, women requiring further follow-up for HPV are often treated in a non-community health setting, most often a cancer clinic or day procedures' area of a hospital (Cervical Cancer in Canada, 1998). In these facilities the health care workers may not be aware of the nature and sensitivity of the transmission of HPV.

This research sets out to speak with healthcare workers about their experiences with working with women with cervical cancer. The central question of this thesis is whether or not this specific clinic uses a women's health approach in working with

women with cervical cancer. This is assessed through the report of healthcare workers' understanding of the attendance of women's specific needs in their policies. Policy, for the purpose of this paper includes any formal or informal guidelines of interaction during patient treatment or care[1]

A women's health approach is defined as one which focuses on "epidemiological differences, andhighlights the specific health needs of womenand girls. This includes a focus on female sexuality and reproduction within a holistic approach to addressing healthneeds across the lifespan" (Horne, Donner & Thurston, 1999, p. 14). A women's health approach encourages the view that women are more than their diagnosis, which allows space for women's psychosocial and physical concerns to coexist rather than compete in the sphere of healthcare.

To begin, this thesis provides a brief history of the medicalization of women's bodies. Through this discussion we see that passivity has been encoded onto women's bodies in many medical treatment situations. Secondly, we look at the importance of the clinical gaze (Foucault, 1973) and its impact on women's ability to make autonomous decisions relating to their care. Following the review of this scholarly literature pertaining to social-historical construction of the female body and the emergence of biomedicine, discussion moves to the research methodology and techniques employed in this study.

This case study traces the history of the clinic in question from its inception, and critically examines policies guiding treatment in part from the teaching/learning materials presently distributed to women. More significantly, the research directly engages policy

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[1] Policy, for the purpose of this paper does not include biomedical treatment guidelines, i.e. evidence-based treatment guidelines including types of medications, types and duration of radiation treatment and any other treatment deemed physically necessary for patients' survival or physical wellness. Rather, policy assessment in this research project focuses on the psychosocial aspects of healthcare worker and patient interaction.

makers and practitioners at the clinic with respect to the current cervical cancer screening and treatment program. These face-to-face interviews focus on the degree to which a women's health approach is present in the minds of the practitioners and in their perceptions of it in current clinic policy. This research adopts a 'women's health' approach as described by Armstrong (1993), which is a health approach focusing on self-help, prevention, promotion and making informed decisions.

Following discussion of the analysis process, presentation of research findings follows in the form of the prevalent themes that arise from this study. The recommendations section sets out to suggest ways in which the women's health approach can be married with the efficacy of best-evidence treatment in order to ensure that women's holistic health needs are attended to when undergoing treatment for cervical cancer.

I Literature Review

In the pages that follow, themes from the scholarlyliterature which emphasize the need for a re-conceptualization of cervical cancer treatment and policy are highlighted. To simplify matters, it is best to consider the reviewedliterature as falling into three over-arching themes:

1. The historicalbeginnings of the biomedical system in the West and its connection to the medicalization of the femalebody.

2. Theincreasing prevalence of cervical cancer in Canada.

3. The current state of health policy with respect to diagnosis and treatment of cervical cancer.

Beginnings of the Medical System and Medicalization

Since modernity, women's bodies have been of particular interest to the world of science. Many feminist scholars argue that women have been the main target of the expansion of medicine (Kohler Reissman, 1998; Schildrick & Price, 1999; Ehrenreich & English, 1979; Pauly-Morgan, 1998). Literature has also analyzed how women's traditional roles of caring for sick and laboring women were expropriated by psychomedical experts in the nineteenth century (Ehrenreich and English, 1979) and the multiple ways in which "women's health in the contemporary period is being jeopardized by a male-controlled, technology-dominated medical care system" (Kohler Reissman,1998, p.47; Pauly-Morgan, 1998, Ehrenreich & English, 1979).

Initially, the emerging domination of women's bodies by physicians in the psychomedical arena was met with some resistance from traditional healers and

midwives, the majority of which were women. According to Ehrenreich and English (1979), physicians positioned themselves as knowing more about treating bodies, when in fact their methods were often grossly unscientific (p.33). While the physicians thus had science and technology, at least in theory on their side, the traditional healers had treatments that had been perfected over hundreds of years[2], and were far more effective than the brutish force of medicine in its infantile stages (Ehrenreich & English, 1979). A prime motivation of early physicians was to professionalize and thus create an economically feasible business that they could dominate and commodify (1979, p.34).

While the profession of medicine was growing, women's bodies became an excellent site from which toconceive and target medicalization. Up until the time of modernity, the bodies of men and women were viewed on a continuum where men were the norm and women a distinct differentiation from men, but the medical sciences began to see women's bodies in opposition to men's. Laqueur (1990) describes 'medical men' as constructing women's bodies as a new and separate identity (p.149). The two-sex model viewed women as opposite but still comparable to men, but continued: "Judged in these terms, women's bodies can only be regarded as anomalous, imperfect and in need of explanation, whereas men's bodies are taken for granted as adequate representations of 'human' attributes" (Grosz & Lepervanche, 1988, p.12). The project of comparing women's bodies to men's was advantageous for the medical profession as it endorsed their need to pathologize the natural functions of women's bodies. Thus, it was the

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[2] It should be noted here that not all midwives practiced under such 'experienced' resumes. Edward Shorter (1982) delineates urban from rural midwives in terms of the degree of organization and professionalism which was more evident in the urban setting. This is to emphasize that not all midwives or traditional healers were equally adept, and that historically physicians were not involved in childbirth. Upon their entrance into the area of childbirth physicians' methods were thought to be 'brutish' in contrast to the more passive, less invasive or natural stance on childbirth historically practiced by midwives (Ehrenreich & English, 1979).

construction of women's bodies as socially problematic that opened the door for subsequent pervasive medicalization (Shilling, 1993).

Though the medical system has evolved in many respects since the nineteenth century, the medicalization and labeling of women's bodies as problematicremains a systemic challenge. Morgan (1998) describes medicalization as satisfying three requirements: the issue must be "definable and defined in medical terms...and must be seen as only appropriately defined by medical discourse" (p.85). The second requirement states that medical authorities are seen as those with the only legitimate treatments and knowledge and thus they "have control over the means and personnel to apply that knowledge to the medically defined 'problem'" (1998, p.85). Finally, "there must ultimately be widespread individual and group acceptance of the dominant conceptualizations of medicalization" (1998, p.86).

Thus, in the case of women's reproductive and sexual rights, medicalization can and will apply to menstruation, childbirth, sexuality, and menopause. According to Cahill, "the successful medicalization of reproduction and its prevention accounts for the majority of consultations between women and doctors" (2001, p.335). Morgan adds that because modern medicine is an institution of social control which makes judgments from a supposedly objective and neutral stance, the way to challenge the 'credentialized expert' is to "demystify and democratize knowledge", thereby eradicating physician monopoly on knowledge (1998, p. 85).

The view discussed above posits that women's bodies were intentionally medicalized and situates the site of this medicalization as occurring on a passive female body rather than an active embodied subject. Conversely, there are scholars, feminist and otherwise, who argue that 'medical men' are not so simply summarized (Sawicki, 1999).

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To cast women as merely passive bodies goes against what feminists have previously theorized regarding women's autonomy. In short, women arguably have never been cultural dopes. Further, while early physicians were exclusively male, the physician population in the West now reflects a more gender representative sample of the population. So we can no longer talk about the 'medical men'. While it is undeniable that the roots of Western medicine lie in a patriarchal historical tradition, women's continued participation in and opposition to medicalization warrants further discussion.

For example, the work of Kohler-Reissman (1998) shows women's motives for taking part in medicalization as class-based expressions of economic interest. Their desire to attain reproductive freedom through technology, for example, contributed to their bodily processes as being understood strictly in clinical terms (2003). She summarizes her thoughts on women's role in the perpetuation of medicalization:

> The medicalization of human problems is a contradictory reality for women. It is part of the problem and of the solution. It has grown out of and in turn has created a series of paradoxes. As women have tried to free themselves from the control that biological processes have had over their lives, they simultaneously have strengthened the control of a biomedical view of their experiences (Kohler-Reissman, 2003, p.55).

Kohler-Reissman also argues that if women continue to seek treatment for physical problems without physicians' recognition or acknowledgement of their social circumstances, their physical problems are stripped of their political context, further limiting any movement away from medicalization (2003). Clearly, while women are not always complicit or for that matter even aware of their role in the medicalization of their own bodies, to state that women have a collaborative role is more accurate than to assert that they are merely passive bodies corrupted by science.

A recognition of contemporary Western medicine as an institution of social control whereby women's bodily processes are subject to medicalization is not meant to imply that women do not have agency; by virtue of making decisions related to their own healthcare they exercise some level of agency. However, the concern is that those decisions are made in oppressive and restricted situations and are therefore not fully autonomous (Sherwin, 1998, Mitchison, 1998, Tomm, 1992). The idea of concrete autonomy poses a problem from a feminist perspective. Autonomy suggests freedom, self-sufficiency and independence - and by using these principles one can guide herself through a decision making process (Sherwin, 1998). However, as Sherwin rightly points out, there are many critiques of the position that one can truly make an 'objective' or 'free' decision that raise the need for an alternative conception of the self which can begin to be achieved through what Sherwin deems a relational approach (Sherwin, 1998; Verkerk, 2001). Using the relational approach we refer to construction of the self as an ongoing process, rather than fixed or static (Sherwin, 1998). Relational selves are constantly changing and reacting to their social surroundings. Sherwin (1998) states:

> By including attention to political relationships of power and powerlessness, this interpretation of relational theory provides room to recognize how the force of oppression can interfere with an individual's ability to exercise autonomy by undermining her sense of herself as an autonomous agent and by depriving her of an opportunity to exercise autonomy. Thus it is able to provide insight into why it is that oppressed people often seem less autonomous than others even when offered a comparable range of choices. Under a relational view, autonomy is best understood to be a capacity or skill that is developed (and constrained) by social circumstances. It is exercised within relationships and social structures that jointly help to shape the individual while also affecting others' responses to her autonomy. (p.23)

Given the understanding of relational autonomy as something that is contextual, not fixed, and not static, the idea of 'informed decision making' needs to be constantly re-evaluated.

Whereas medical research often takes on a positivist perspective which makes implicit assumptions about fixed and static entities, it is important to reflect on the nature of relational autonomy and the realities it represents for women's healthcare. Although we would like to assume that all women can/will want to be involved in the decision making process there needs to be reflexivity on the part of healthcare providers regarding the personal circumstances that may at any given time affect a woman's ability to be more or less autonomous. This does not deny or diminish agency, but it does, in effect, suggest degrees of autonomy active in agency.

herstory

To illustratefurther the historical origins of the medicalization of women's bodies a brief history follows.This is to provide some insight into the historical origins of medicalization as well as to illustrate the evolution of healthcare delivery. The following section is set out to demonstrate the ways in which women's bodies have historically been recipients of medicalization. The account is not meant to be an exhaustive review of the pertinent historical literature which details internal debates, but rather an introduction by way of three examples to the major forces shaping the conceptualization of women's reproductive processes in the West. These three examples are childbirth, hysteria and sexuality.

I. Childbirth

Up until the mid 1760's, most women delivered their babies at home. This momentous occasion was normally attended by a group of women and at least one midwife (Leavitt Walzer, 1986). The women were called together, and would be together from the time of the birth until as late as one week after; men only participated when

women were unavailable and medical intervention was only accessed when the labour did not progress, or a dead fetus needed to be extracted (Leavitt Walzer, 1986). Women were said to suffer through childbirth experiences together, sharing support through the excitement of birth and the grief when a child was lost (Leavitt Walzer, 1986). This was said to be the social aspect of childbirth which became the cornerstone of women's groups. The aspect of childbirth as a social activity was less relevant when modern medicine entered the sphere of childbirth and introduced technology.

Around the mid-eighteenth century medical doctors began to take part in childbirth (Leavitt Walzer, 1986). Prior to this time, pregnancy and childbirth were seen as natural events, but with the advent of the new medical profession, women were relegated to a new space. The job of delivering babies was seen as something that midwives were not of sufficiently sound mind and expertise to perform. Though it was controversial for physicians (most often men) to be entering this very private sphere, they entered boldly, as it was for the perceived greater good of women's health. This is how the medicalization of women's bodies was stratified from its origin.

Cahill states (2001):

...this medicalization of pregnancy was achieved over time, more through ideological claims to greater medical expertise (Oakley 1980), than any demonstrable benefits to women. Donnison's (1977) argument that the medical men deliberately set out to frighten women into believing that male attendance was necessary by exaggerating the dangers of childbirth, still holds true in contemporary maternity care...[and there is] compelling evidence that indicates the involvement of men in childbirth around the turn of this century brought new hazards to mothers and babies rather than greater safety; the increased transmission of fever and injuries associated with careless use of technology, especially the forceps (p.338).

This account describes to us the implications of the medicalization of childbirth and how the continual presence of medical technology in childbirth resulted in more and more

dependence on modern medicine. Cahill explains that the use of forceps and other tools often led to further complications requiring surgical intervention, and the further need for the technological exploration of women's bodies (Cahill, 2001).

Medical intervention in women's laboring was clearly predicated on the need for modern medicine to gain status and by socially constructing women's bodies as helpless and problematic objects, the scale and sphere of its influence was broadened. Soon the 'age of obstetrics' arrived. Barker-Benfield (1976) describes it as an explosion of interest in obstetrics and gynecology, which led to the well-documented implementation of many unnecessary surgeries and procedures. The age marked the institutionally legitimized onset of the medicalization of women's reproductive life cycle.

Shorter (1982) also argues that middle-class women welcomed the entrance of physicians and male birth attendants. While poor and working class women could only afford to have a midwife, affluent women were attended by physicians. Similarly, working class women would have their babies and go back to work the next day, whereas upper class women would follow the physicians' orders and maintain bed-rest which was at times a week or more. Thus, the relationship between the physician and the woman of the emerging middle class was symbiotic - his presence was a status symbol for women and a way for physicians to gain prestige among the most important of their clients (Shorter, 1982).

It should also be stated that owing to their modesty women historically have been complicit in the lack of understanding and exploration of the area of gynecology. Until the 1800's, just before the era of obstetrics launched, women were under such a veil of protectionism that this did affect their medical care (Tannahill, 1990). This however was a tenuous and dangerous compromise, especially when this modesty was reinforced to the

detriment of a serious medical condition. Tanahill (1990) states that sometimes, with the aide of a chaperone, a physician would do a pelvic exam under a sheet in a blackened room. If this was considered too invasive the physician might ask the woman to indicate her pain on a lay person or model. There were physicians who even encouraged women's demand to maintain modesty. One physician stated he was "proud that in America 'women prefer to suffer the extremity of danger and pain rather than waive those scruples of delicacy which prevent their maladies from being fully explored'" (Tanahill, 1990). Therefore, while women were arguably complicit in this protectionism in favor of maintaining prevailing social standards of female decorum, some physicians reinforced it.

2. Hysteria

Further medicalization of women's bodies is well illustrated by the over/misdiagnosis of the questionable condition known as hysteria. Crimlisk and Ron (1999) state that hysteria is derived from the Greek word hystero, meaning uterus. According to Mitchison (1988) 'reproduction processes' were seen as creating stress on the system and were therefore considered disease-like. By virtue of women's bodily processes in comparison to the self-contained male body, female bodies seemed highly irrational and volatile. Schildrick and Price (1999) state:

> The very fact that women are able to menstruate, to develop another body
> unseen within their own, to give birth, and to lactate is enough to suggest a
> potentially dangerous volatility that marks the female body as out of
> control, beyond, and set-against, the force of reason (p.3).

One theory prevalent during the Victorian era was that hysteria resulted from a wandering uterus disturbing the mind, which further emphasizes the degradation and distrust of women's bodies (Scheurich, 2000). While in Canada the diagnosis of hysteria did not occur to the same extent as it did in other countries such as the United States, the lesser

procedure of cauterization was advocated in the text books of nineteenth-century Canadian physicians (Mitchison, 1988, p.94). In the United States, physicians advocated for the excision of the clitoris which was seen as the root cause of women's hysteria.

3. Sexuality

Sexuality was also an area where women found themselves in a compromised position. According to Shorter, upper and middle class women often refused sex with their husbands and had the autonomy and good sense to do so (1982). In contrast, working class married women had very little choice in the matter; sex with their husbands was not seen as an option but an obligatory duty. This prompted a problem which was two-fold: working class women often had no access to contraception and were therefore burdened with numerous pregnancies and middle/upper class men were often left looking for other avenues for sexual pleasure (Shorter, 1982).

Amongst those women who were not married and were not of an upwardly mobile class, prostitution was considered a common and quasi-acceptable job. The acceptance of prostitution as a common choice for working class girls, whilst middle-class women remained at home, seemed to be a fundamental contradiction, but again, modern medicine had proclaimed "sex with a prostitute where neither love nor passion was involved "was generally attended with less derangement than sex with a wife""(Tannahill,1982, p.353). Thus it seems that the medicalization of women's bodies not only meant that their bodies would be a site for intense medical scrutiny; it also created a new dichotomy of sexual behavior between upper and lower class women[3].

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[3] This is not to presume that upper-class women were not having sex. By virtue of having children there was sexual intercourse taking place, but it was largely for procreative purposes (Tannahill, 1992).

Because middle-class women were excluded, lower/working-class women were sexually exploited - thought of as less fragile seconds who were seen as more fitting to meet the sexual needs of men. This seemed to construct a class based whore/madonna dichotomy among women, which further problematized the way women viewed themselves and their bodies.

Although much has changed regarding the perception of women and their right to partake in sexual activity, many argue that female sexuality has not evolved as expected. Women may no longer be considered too fragile to be part of a sexual relationship, but some theorize that the prospects of their sexual relationships are bleak (Ehrenreich & English, 1979). Ehrenreich and English (1979) theorize that the old view of sex where middle class women were viewed as fragile and in need of protection was rationalized by a paternalistic love and nurturance, which became an oasis in a desert. Beginning in the mid twentieth century with the widespread marketing of the birth control pill,they claim, sexual activity for women became merely a desert with no promise of any sort of respect or nurturance aside from sex (p.319). LeMoncheck (1997) also supports the idea that, for women, being able to engage in a promiscuous lifestyle was vastly overrated (p.27):

> Pleasures of promiscuity promised by the postwar sexual revolution have been complicated by much more than the fear of AIDS. While their increased economic independence and reproductive choice have given many middle-class women the freedom to pursue sex outside of marriage, this freedom has not come without a price…many men have less incentive to take responsibility for family planning or family support (p.27-28).

Womenmay have wanted to exercise sexual freedom, but it was complicated by the need for the political and economic sites to evolve along with the evolution of their sexuality. With access to legal and reliable birth control, as well as legalized abortion, women's bodies were somewhat placed back in their ownhands, but only in the sense that they

could engage in sexual relationships more freely. With legalization, the issues of control and self-surveillance were only further complicated.

According to Shilling (1993), as late as the 1970's, women were making gains in the direction of physical equality to men, but their bodies were again the targets of medicalization. As women rallied for power in political and social spheres, medical men spoke out to say that women were controlled by their hormones and that at the time of pre-menstruation they were rendered erratic and unreliable (Shilling, 1993). This was a convenient time for such an assertion, as women were beginning to enter the spheres that men had often dominated - this was men's way of retaining social control. Female inferiority was re-entrenched through the pathologizing of their bodies; menstruation was viewed as a disability which controlled women's emotions and intelligence (Shilling, 1993). This discourse from the 1970's arguably remains active in medicalizing women's bodies to the present day. For example, Stoppard (1992) argues that the labeling of premenstrual syndrome (PMS) has furthered negative views of menstruation, affecting women's ability to view their bodies and menstruation positively.

panopticism and the clinical gaze

While childbirth, hysteria, and menstruation were continual sites for women's medicalization, the process was further complicated by the inauguration of the medical clinic. As discussed above, traditional healers and midwives visited women in the home, but upon the inception of modern medicine, women were required to leave the comfort of their home to attend the unfamiliarity of the clinic (Ehrenreich & English, 1979). While the clinic presented itself as a hygienic and protective place, what it also created is a site wherein which the medical gaze could come into full realization. As Foucault (1973) states:

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...this constant gaze upon the patient, this age-old yet ever renewed attention that enabled medicine not to disappear entirely with each new speculation, but to preserve itself, to assume little by little the figure of a truth that is definitive ...In the non-variable of the clinic, medicine, it was thought, had bound truth and time together (p.55).

The philosophy of the clinic was in keeping with what Jeremy Bentham (1843) referred to as the panopticon and what Foucault reconceptualizes as applicable to many institutions, including the medical clinic (1973, 1979, 1995).

The concept of the panopticon is captured through the notion of watchfulness. Bentham had originally proposed the idea in regards to an architectural design of a prison which allowed one guard to see every inmate from a specific point, creating a threat of ongoing visibility and watchfulness. In *Discipline and Punish* (1995), Foucault claims that surveillance became and still is a crucial aspect for the functioning of discipline. According to Holmes, "Disciplines are ... 'methods', which made possible the meticulous control of the operations of the body, which assured the constant subjection of its forces and imposed upon them a relation of docility - utility" (2001, p.8). But the ongoing visibility of the panopticon becomes the ultimate trap for the patient or prisoner. Constantly aware of the scrutiny of the gaze, they begin to monitor themselves. That is, the watchfulness is turned upon itself, and self-surveillance begins even if no one is watching. Constantly cognizant of that possibility, one engages in the perpetual self-monitoring because of 'feeling' continually scrutinized. "The observed and the observers cannot escape the gaze of this eye of power and its powerful effect" (Holmes, 2001, p.9).

A feature of the clinical gaze which makes it most effective is its association with no one:

> The gaze posed on the patient is anonymous. The invisibility of the observer permits anonymity and impedes association with power to a special figure or person...The disciplinary machine is fundamentally democratic as it hides the ones who watch. No one is responsible for it. Everyone is, and everyone is caught in it no matter the status of the institution" (Holmes, 2001, p.11).

Everyone, patient and practitioner, is caught in the panopticon of the clinic - the clinical gaze affects those who are looked upon as well as those who do the looking. Whilst the panopticon metaphor refers to an illusive concept of watchfulness, the original architectural ideal is also recreated through the physicality of clinic environments. The clinics where women are treated for cervical cancer often employ spatial organizations to permit staff the opportunity to constantly observe the patients, literally employing panopticism to cast the clinical gaze upon women (Barnes, 2000).

Pryce (2001) asserts that it is precisely the panopticon atmosphere created by clinics that create an oppressive and uneasy atmosphere for women's health decision making, thereby influencing their autonomy. According to Pryce, the 'active patient' results from the disciplinary power employed through a panopticon-like environment which results in the need to continually examine oneself, employ self-care practices and health promotion strategies (2001, p.151). Pryce's analysis is effective because he is looking specifically at the 'duties' of the STI/D clinic, wherein the process of cervical cancer treatment or diagnosis often begins due to its closely-knit etiological relationship with HPV.

The impact of the panopticon concept can be summarized as implying a constant state of watchfulness upon someone, along with the secondary, (though no less critical)

effect of self-surveillance. While one cannot be sure of the positive or negative impact this has on the patient, the effects of the panopticon are arguably unavoidable in most social institutions. Thus, in the clinic environment not only is the gaze apparent via the policies affecting women's health, but also in the atmosphere of the physical space itself.

prevalence of cervical cancer

Cervical cancer has become one of the most common neoplastic[4] diseases affecting women in the world, second only to breast cancer (Franco, 2001). According to the Public Health Agency of Canada (PHAC), since 1969, mortality rates from invasive cervical cancer have fallen from 7.6 per 100, 000 females to 2.4 in 100, 000 in 1992. Despite the drop in invasive cancers, there has been a marked increase in incidence of in-situ carcinomas from 12.3 in 100, 000 women in 1955 to 133.6 in 100, 000 in 1985 (Public Health Agency of Canada, 2005, Liu, Semenciw, Probert & Mao, 2001). In situ carcinoma means that there is a cancer affecting the lining of the epithelium or surface layer of the tissue, a cancer in its early stages which can be easily managed with superficial treatments and early diagnosis (BC Cancer Agency, 2000).

The increased incidence of non-invasive cervical cancer can be most closely linked to the increase in HPV. According to Furumoto and Irahara (2002) high-risk HPV has now been isolated as the main etiologic factor in cervical cancer. HPV is an infection that is sexually transmitted, and in some strains it manifests itself in the form of warts on the mucosal areas of the genitals, anus and mouth. This same virus has cancer-causing effects on the cervix. The rate at which any given strain of HPV will cause cancer is dependent on the type of HPV. According to the World Health Organization's

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[4] Neoplastic or Neoplasm is the term for a group of cells characterized by rapid uncontrolled abnormal cell growth. The term tumor and neoplasm are often used interchangeably (Tortora & Derrickson, 2006).

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International Agency for Research on Cancer (WHO) (IARC) (as cited in Franco, Franco-Duatre, & Ferecenzy, 2001) stated that HPV infection has been classified as "'carcinogenic' to humans (HPV types16 and 18), "probably" carcinogenic (HPV types 31 and 33) and "possibly" carcinogenic (other HPV types except 6 and 11)." In a study by Sellors et al. (2003) the highest rate of HPV was among 19-25 year olds, who have a 24% infection rate, and those who were infected with types 16 or 18, which was about 10 percent, were most likely to develop cervical neoplasia and cancer[5].

Given that HPV is a sexually transmitted infection and cervical cancer is a chronic disease, in treating this group of women there are two factors that need to be addressed and which present a challenge for those who carry out their treatments and education. Treating women for sexually transmitted illnesses has been historically problematic because of the associated stigma[6], while treating one for a chronic disease also brings a special set of considerations (Tannahill, 1982, Malterud, Candib, & Code, 2004). In three qualitative studies on pap-test results, many women described feeling confused by the findings and not being given thorough or conclusive information from their physician (Karasz, Mckee, & Roybal, 2003; Meana, Stewart, Lickrish, Murphy & Rosen, 1998, Monnet et al., 2004). Because the scrutiny of the clinical gaze cast on those who engage in 'high-risk' sexual behaviors can clearly affect rates of diagnosis and treatment outcomes, the integration of policies which are sensitive to women is essential.

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[5] I will acknowledge briefly the recent implementation and controversy regarding the HPV vaccine. Abstinence-only advocates have appealed to parents to disallow vaccination of children (Couto & Dailard, 1999, p.1), while advocates of the vaccine note the disproportionately high rates of cervical cancer among the poor and non-white populations (Dailard, 200, p.6). Other objectors believe that the rate of infection of cervical cancer from HPV is relatively low and that the risks of the vaccine outweigh the potential benefits (Melo-Martin, 2006, p.393).
[6] Stigma is associated with delays in treatment, poor health outcomes, guilt, isolation, fear and denial (Lichenstein, 2003; Batelle Report, 1998; Gilmore & Somerville, 1994).

According to the popular handbook, *Our Bodies, Ourselves,* women in North America are the majority users of the healthcare system due to the fact that they are more often the caregivers of children and the elderly, and also because women face unique health problems (Boston Women's Health Collective, 1998). Similarly, Spitzer states that economic status has a significant impact on health, and the average lifetime earnings of women are only 67% that of males (2005). Spitzer also points out that male life expectancy is 76 years, while their female counterpart can expect to live until 81 (2005, p.80). However, the additional years lived by the female are 7% more likely to be plagued with chronic illness, where 11% of women suffer from chronic conditions that only 4% of men suffer from (Spitzer, 2005, p.80). That said, with women's earnings at 67% that of men's and with economic status affecting health outcomes, women's health policy needs to reflect the short comings that are implied by virtue of their gender.

Women's health may also be affected by their role as caregiver. Due to the restructuring of the healthcare system, many elderly people must be cared for in the home, and this work often falls towomen. Spitzer pointsout that the North American woman will spend an average of 18 years caring for an elderly spouse and 17 years caring for children, and in this role, women are more likely to forgo their own health needs in order to maintain their role of caregiver (2005, p.81). Women's health policy therefore needs to be attentive to the additional stressors placed on women.

Further, the health of many women is clearly affected by virtue of their reproductive capacity. That is, if reproductive health was excluded from consideration, women and men would access the healthcare system nearly equally (Spitzer, 2005, p.81). According to Munoz et al. (2002), parity and other cervical trauma increases the risk of

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cervical cancer. Thus by virtue of having children, women are at an increased risk of contracting cervical cancer.

Women's health is also significantly determined by other social factors that affect their lives. The discussion above touched on income, parity, and women's traditional role as caregiver, all as factors which negatively affect their health. Because women experience unique illness and disease, it is a necessary that health policy be specifically tailored to the needs of women experiencing illnesses such as cervical cancer. There is an inherent need to create policies which target the realities of women's lives, using approaches that are sensitive to the specific needs of women's demanding lifestyles. Through said approach women can expect programs to be developed with outcomes that address their unique health needs.

In 1999, Health Canada implemented the Women's Health Strategy (WHS), whose goals are "to (1) promote understanding of the distinct nature of women's health issues; and (2) address the biases and insensitivities of the health system to women and their issues" (Women's Health Strategy, 1999). The WHS indicates four biases in the system that may affect the health of women: narrowness of focus, exclusion, treating women like men, and treating women differently than men at inappropriate times. The components of this women's health strategy set out specific parameters for policy development regarding women's health.

Near the time of the implementation of the Women's Health Strategy by Health Canada, Gender Based Analysis (GBA) policy was published and considered active in health policy development (Carron, 2003). GBA implementation is an ongoing project and GBA tools and training modules have been made available to encourage gender-sensitive research initiatives by policy makers. The merits and importance of GBA are

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outlined in *Exploring Concepts of Gender and Health*, a document from Health Canada. This document emphasizes that the implementation of GBA is not an add-on, but ratheris integrated into each step of the research, policy and program development. GBA also encourages substantive equality through involving stakeholders in decision making and utilizing a firmly evidence informed approach (Health Canada, 2003). Through the commitment to the implementation of GBA in government research and policy making, women, as stakeholders in cervical cancer treatment programs should expect to be involved in the research process.

While women's health has evidently become an issue which is seriously considered by government agencies and national think-tanks, innovations in research have not translated into subsequent policy creation. The most recently released federal guidelines regarding cervical cancer treatment are contained in the*Programmatic Guidelines for Screening for Cancer of the Cervix in Canada*[7] (1998). The document is intended to outline treatment guidelines based on the best available research, and evidence-based practice. It is a document developed by a collective with the goal of creating best practice guidelines for practitioners at a federal level. The document was created by several very notable collectives including The Society of Canadian Colposcopists[8], the Society of Gynecologic Oncologists, the College of Family Physicians of Canada, the Society of Obstetrics and Gynecologists of Canada, and the Canadian Society of Cytology. While this document does provide the best available evidence on the treatment and management of cervical cancer treatment it refers only to

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[7] This document contains the only set of treatment guidelines developed nationally and publicly available. The probable reason for this is that clinics generally develop guidelines specific to their practice and relating to their specific needs.

[8] " Colposcopist" refers to one who performs a colposcopy. The colposcopy is the procedure whereby a biopsy is taken from the tissue of the cervix (Schneider et al. 2000). This procedure is reserved for a medical doctor or an expanded role nurse practitioner.

the biomedical aspects of treatment and care. It does not take into account the voices of the women for whom the treatment is targeted. It is written purely from a clinical point of view, and most likely by administrators and physicians. Ironically, the cover of this report is adorned with representations of average looking women of all ages, and yet their faces represent the lack of psychosocial attention. The point here is not to detract from the importance of evidence-based practice, certainly best evidence is needed for successful treatment of cancer. Attention does need to be drawn to the absence of consideration of psychosocial concerns that have great impact on mental and physical wellness.

Armstrong (1993) emphasizes that women's voices were an integral part of the women's health movement which began in the 1960s. That is, women wanted to be involved in the process of healthcare and not be led into a top down inductive process (p.133). Similarly, Amaro, Raj and Reed (2001) argue for the importance of conceptualizing women through a feminist perspective as was the case in the early days of the women's health movement (p.324). Armstrong and Amaro et.al. describe a regression from the 1960s movement toward again classifying women according to a biomedical model instead of through a model of empowerment. This policy literature literallyrepresents what is missing, and where new policies are needed.

Rosen (2004) describes the disconnection between healthcare administrators and clinicians in postulating the cause of the meaningless policy documents which are continually produced by governments and which are frequently under-utilized. Wakewich (2000) also takes the viewpoint that women's inclusion in policy making is not a priority:

...laywomen's perspectives on health and illness remain largely absent from the 'data' gathered for healthcare decision making and planning. Rather, policy development relies on the expertise of healthcare professionals on the one hand, and key informants such as community organizations and women's groups on the other hand (p.238).

Though the women's health strategy and GBA imply the need to understand the individual voices and experiences of women, there is no actual evidence of this taking place in the policy-making process from which the treatment guidelines emerge. The women's health disconnect is arguably even more complex, where women's health activists and non-physician clinicians (nurse practitioners, nurse clinicians, etc.) try to form collectives to educate women in a more deductive and participatory way. At the same time, the physicians and administrators continue to adhere to hygienic methods of research and policy because these processes are less messy and more familiar to the general public. In short, regardless of the specific cause of the inability to translate research findings into policy, what is certain is that a major barrier with knowledge transfer exists.

According to the Canadian Health Services Research Fund, the application of research findings to health policy cannot be guaranteed. That is, we cannot expect that the knowledge generated will be transferred to or received by policy makers because of the multiple groups involved in the process of research development (Canadian Health Services Research Foundation). Moreover, "evidence-based policy is difficult to achieve and it is widely agreed that health policies do not reflect research evidence to the extent that in theory they could" (Haney, Gonzalez-Block, Buxton, & Kogan, 2003). Lavis, Ross and Hurley argue that researchers need to form relationships with politicians and policy makers in order to ensure that the knowledge transfer cycle is carried through (2003). Though it seems useful for researchers to join forces with policy makers, research

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is their commodity and they will not easily comply with a model of seeking out policy makers. The policy makers must become active in the pursuit to engage in the process of finding the research and making it available to the public through policy and publication. While this might solve the problem of knowledge transfer, it would also reconcile the gaps among policy, research and practice and integrate the voices of health care users into healthcare documents.

Knowledge transfer is not limited to issues regarding women's health. Rather, it applies to all those who produce research in hopes of creating policy change. But in order to actually effect the desired change there are many strategic steps that need to be taken. The Children and Women's Health Centre of BC describe the ways in which they ensure that knowledge is transferred in order to keep them in best practice:

> BC Women's is committed to continuous and iterative improvement of its clinical care, training and outreach. Consistent multi-sectoral involvement throughout the entire research process guarantees more effective knowledge transfer to clinical, policy, community and academic audiences. Multiple approaches and formats for appropriate and effective dissemination are a measure of success of our research. This approach is increasingly encouraged and desired by funders, researchers and communities (The children and women's health centre of BC, 2001).

The objectives highlighted above are achieved through partnerships that ensure the exchange and dissemination of research results. This commitment creates change that permeates the academic and policy community and changes policy which has the potential to create improved health outcomes for women and men accessing the health system.

Health policy drafted specifically for women, however, implies that we concur on a definition of woman as a concrete category. While attempting to recognize the differences and eccentricities in women's health experiences, we need to draw on a

definition of woman which is concrete. Catherine Mackinnon (1996) is aware of the reductive assumption of drawing on an essential woman, but she refutes postmodern ideals in the sense that there are specific things that are 'essential' to women. She states:

> To speak of social treatment "as a woman" is not to invoke any abstract essence or homogenous generic ideal type, not to posit anything, far less, a universal anything, but to refer to this diverse and pervasive concrete material reality of social meanings and practices such that, in the words of Richard Rorty, "a woman is not yet the name of a way of being human..." (1996, p.48).

It isMacKinnon's incisive definition of woman that is used to refer to the group of women who receive cervical cancer treatment in the research that frames this thesis. They will be considered female by virtue of their biology; more specifically by virtue of having a cervix. Germaine Greer makes a similar assumption in her work,*The Female Eunuch* (1971). However, for Greer, referring to women as a collective category on the basis of reproductive anatomy was not a contestable action, whereas postmodern theorists such as Elizabeth Spelman now argue that deeming women as having some hidden thread connecting them embarks on the road to 'essentialism' (Spelman, 1990). While I agree with Spelman, this research invokes the term "woman" to refer to a feature of dominant discourse whereby some persons are categorized as "women" because their reproductive organs are of central concern to their identification.

Cervical cancer screening, however, does involve a heterosexual assumption that should be acknowledged. Simply put, women are asked to begin screening at the age of 18 because this is thought to be an age when most women are sexually active. While most documentation distributed to young women preparing to be screened does not specify that heterosexual activity is of greatest concern, generally the type of sex linked to cervical cancer transmission by HPV is heterosexual. However, women are clearly not a

homogenous group and have a diverse array of sexual partners and preferences. The purpose of setting treatment standards however, as with this research, is to capture a population, where the commonality is the potential risk for cervical cancer and the prevention is screening by pap smears.

Conclusion

This chapter provided a thematic summary of pertinent literature to guide the reader in respect to the social-historical forces shaping the female body and the biomedical approaches to them. The substantial focus in this chapter is on literature regarding the history of women's bodies and the subsequent roles of biomedical science, physicians and women themselves in the creation and perpetuation of medicalization. The chapter concludes with evidence showing the need for clinic case studies and the like, especially those that emphasis the need for analysis and implementation of a women's health approach and gender-based analysis.

II Methodology, Ethical Considerations & Limitations

The project undertakes a feminist case study[9] of a cancer clinic in an urban center

located in the province of Saskatchewan. Reinharz states that case studies are "used to

illustrate an idea, to explain the process of development over time, to show the limits of

generalizations, to explore uncharted issues by starting with a limited case, and to pose

provocative questions" (Reinharz, 1992, p.167). Because a case study analyzes only one

clinic its findings are not empirically generalizable, but it does provide insight into

existing policy and suggests how changes can be made both to advance existing stategies

and to makethem more woman-centered.

This case study of a cancer clinic in an urban center locatedin the province of

Saskatchewan involved three central data components:

I. A review of the history of the clinic as accessed through institutional materials dating

from its inception.

II. A review of the teaching/learning documents that are distributed or made available to

women who attend the clinic.

III. A review of the cervical cancer treatment policies (as described by participants) using

semi-structured, open-ended interviews with policy makers and practitioners employed at

the clinic (See appendix I).

The case study method was selected in order to look specifically at the goings on

of one clinic. While clinics are highly intricate operations they are largely under the

control of the bio-medical model and the medical hierarchy, and in discussions with those

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[9]According to Robson (1993), a case study is "a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence" (p.146).

who work within the clinic, we could begin to understand the sum of all of the parts. By interviewing those who work at the clinic, rather than those who attend the clinic it is possible to gain insight into the perceptions of those who carry out treatment, which, as you will see, significantly affects the way women receive treatment.

The case study method thus provides a significant analysis of one clinic and while the results are not empirically generalizable, they provide insight into the functioning of this institution. While recommendations deduced from this research may not be applicable to treatment in another jurisdiction, it is possible that aspects of the recommendations may have a certain degree of transferability. The case can also be made that generalizability is a redundant concept in the context of the case study. That is, the richness of this case-specific data preludes the need to be generalizable (Bergen & While, 2000). Also, empirical theory generation is not the goal of this research project, but rather the theoretical explanations of the clinic's functions. This sentiment is similarly emphasized by Sharp (1998):

> Case studies, which cannot claim to be typical of some parent population, may be used as the basis for generalization, but this generalization would be theoretical and not empirical in nature. Case studies are, in short, a means by which theoretical explanations of phenomena can be generated (p.788).

The case study method also emphasizes the importance of "in-depth investigation of a particular unit or institution" and this was certainly the goal of the research project (Bergen & While, 2000, p.927).

The feminist perspective utilized in this research is not a method, but rather a perspective which influences the methodology of the research, the way data is collected and its outcomes. Greenbacks states that:

> Researchers are acknowledging the influences of values on the research process. They are also recognizing the need to accommodate values in their research. One approach advocates that researchers should include biographical details and make a statement about their underlying values (Skeggs, 1994; Williams, 2000). Whilst this may not result in eliminating or reducing the effect of values (Walsh, 1999), it enables those evaluating research to take account of the values that are influencing the work (Gummesson, 1991) (p.795).

And so, in acknowledging that human beings are the subjects of this study and that a human being is collecting and analyzing the data, the following discussion engages in an exercise in reflexivity.

Interviews

In order to step back from a notion of objectivity, and to allow participants to narrate their own stories I chose to conduct face-to-face interviews with participants in the case-study. "The use of semi-structured interviews has become the principal means by which feminists have sought to achieve the active involvement of their respondents in the construction of data about their lives" (Graham, p.112, 1984). For example, while participants are asked questions pertaining to work realities and practices rather than their lives outside of work, arguably the two can not be easily separated. Open-ended and semi-structured interviews, as opposed to surveys, provide quality rather than quantity of data by allowing participants to narrate the research as they see fit.

The interviews were carried out using a conversational format. Each participant was given a copy of the questions to guide the interview and we addressed only the questions which the participant wanted to answer. The interviews were audio-taped with

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the permission of the participant, which enabled me to give the participant my full attention. Reinharz (1992) emphasizes the importance of participants' ideas, and of allowing them to describe their thoughts and ideas in their own words. By allowing participants to speak openly about their experiences, the researcher can generate theory about these experiences (Reinharz, 1992, p.19).

While the basis of the methodology is the case-study method, aspects of institutional ethnography (IE) have also been woven into the research. My interest in IE arises from Dorothy Smith, who sees that "the social arises in peoples' activities and through ongoing and purposeful concerting and coordinating of these activities" (Cambell & Gregor, 2002, p.27). According to Dorothy Smith,

> Institutional ethnography begins by locating a standpoint in an institutional order that provides the guiding perspective from which that order will be explored. It begins with some issues, concerns or problems that are real for people and that are situated in their relationship to an institutional order. The concerns are explicated by the researcher in talking with them and thus set the direction of inquiry (2005, p.32).

Certain features of the IE method were deemed especially suitable for this case study. The main research question guiding this project was to assess the degree of a women's health approach evident in the clinic's policies with respect to cervical cancer treatment, not to invite the concerns identified by the interviewees. IE was useful, however, because by definition it implies that the research initiative must be interdisciplinary. To understand relationships across and between the clinic's policies as well as to interpret the views of various medical personnel, a discipline-specific approach was unwarranted. Similarly, IE emphasizes making use of society as it is and attempting to learn the intricate puzzles without modification. In other words, the questions IE is interested in is how these puzzles are organized (Campbell & Gregor, 2002).

Because the research is the study of a single case, I am interested in the specific connections within the organization. More specifically, the research focused on the development and daily interaction with clinic policies: Who is using them? For whose benefit are they created? Who or what is the vehicle for potential change? These are all connections that can be unraveled with the assistance of the IE methods. All of this is in pursuit of understanding how policy is developed and whether women are actually at the centre of the policy development. "The inquiry is all about circumstances located in the world of the subject, even if it is outside the subject's experience and knowledge" (Campbell & Gregor, 2002, p.59).

As previously mentioned, other sources of data for the project include policy documents and teaching/learning materials pertaining to the treatment of cervical cancer. Treatment policies were assessed specifically, and government documents and standards of practice were compared to the federal treatment standards in order to discern whether discrepancies or differences in treatment existed, and for what purpose these policy differences exist. Documents from Health Canada, Saskatchewan Health, Statistics Canada, Saskatchewan Cancer Care and other related policy papers were also reviewed. Teaching/learning materials from the clinic were analyzed to assess their relevance, veracity, appropriateness and also to assess the level of women-specific or women's health content.

Primary data collection

Primary data collection was initiated following approval from Saint Mary's University Research Ethics Board in September 2006. Previous to receiving ethical approval I had been in discussions with the Director of the clinic in order to ensure their interest in cooperating with the study. Upon ethics approval, the clinic director was

immediately contacted to notify him that data collection would be commencing. At this time written consent from the director as well as contact information of employees at the clinic was obtained.

This specific clinic was chosen for reasons for several reasons, none of which is more important than the geographic location in proximity to my place of residence. While there are clinics that claim to be women centered and have implemented self-help initiatives, this was the only cancer treatment center in this city. Similarly, because this was the only clinic in the area, women did not have an option to go to another clinic, which was more women-centered or suited to their needs. The clinic's generic approach to care was suitable because it represented the norm of care delivery within the province. Similarly, while this clinic did not profess to be a well-woman clinic, gender-based analysis guidelines indicate that clinics should be practicing under these gender-sensitive guidelines even outside of 'special' clinics.

At the onset of the primary research, one of the main strategies of institutional ethnography was utilized. Cambell and Gregor (2002) state that institutional ethnographies are rarely planned out in advance, rather, the researcher knows what they want to explain, but only step by step do they target specific interviewees. The first meeting was with a physician in the treatment facility, who then suggested the nurse that he primarily works with, and several other professionals for whom he gave me the contact information. Initially, a total of 15 personnel from the clinic were targeted for individual interviews. All worked in areas of direct patient care and in the practice areas of pharmacy, nursing, psychosocial oncology, medicine and radiation therapy.

From the potential 15, 9 individuals were interviewed in total, owing to the fact that several could either a) not find an appropriate time to meet or b) gave their name only

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out of obligation to their superior and then chose not to be involved once they discovered what the research was about. On the bright side, the participants who did take part in the research displayed a genuine interest in the study. In all cases personnel at the clinic were thanked for their time, even if they later declined to participate.

All 9 interviews were completed face-to-face during September and October of 2006, while one interview took place in December 2006 due to scheduling constraints. While the data were thematically saturated after 8 interviews, the 9th was completed because of the participant's significant role at the clinic. Of 9 interviews, 7 were conducted at the cancer clinic while 2 were conducted at participants' private offices off-site. Of the interviews conducted at the clinic, 5 took place in participants' offices. Of the remaining 2 interviews, both took place in empty treatment rooms - neither participant seemed uncomfortable sharing their thoughts while in a treatment area. The participants were mostly female (7 of 9), and all had some type of post-secondary education in order to qualify for work at the clinic.

Each interview marked my first encounter with the interviewee. I presented myself at the reception area of the clinic and the participant was notified of my arrival. Once we met, the participant would lead me to wherever they had planned the interview to take place. I would start the interview by introducing myself, my program of study and the nature of the research. I would then provide them with a copy of the list of questions (see appendix 1), the goals of the research (see appendix 2) and the consent form (see appendix 3). I informed them that the interview would be taped with their permission and tell them to let me know if they wanted to stop at any time. If there was any need to answer the phone etc., we would stop the recording. By allowing the participant to speak openly (s)he could lead the interview and be the leader in the project, thereby generating

first-hand knowledge regarding treatment approaches at the clinic (Letherby, 2003). Because this was a work setting, ringing telephones and knocks on the door were expected and respected.

The length of the interviews ranged from approximately 25 to 45 minutes. On occasion, time was limited and because the interviews were conducted at the workplace, it was possible that interviewees were somewhat cautious of what they said. That is, some of the semi-structured questions were designed to elicit non-medical, more social or opinion-based answers, and at times tension and self-censorship seemed evident in interviewee responses. Perhaps participants were afraid to say things for fear of negative consequences because it was their place of work or perhaps I was being overly sensitive to factors affecting disclosure.

In order to experience the research process more fully, I transcribed all 9 interviews either immediately after an interview or in the weeks that followed. The process was surprisingly tedious, but an indispensable way to get back to the data and to absorb and analyze what had taken place in a holistic manner.

Print materials

As previously mentioned, one of the data sources accessed was the educational material distributed to the women requiring treatment at the clinic. The material was provided to me during one of the initial interviews with a psychosocial oncologist and included a brochure which provided a general orientation to the cancer clinic as well as generalized treatment information.

While the proposed research included an overview of the clinics materials from its inception, the search for these materials proved to be less fruitful than anticipated and

certainly became less relevant as the research took shape. While the history of the clinic is important to its current functioning, there was nothing that was seemingly out of the ordinary in terms of the biomedical paradigm of clinic establishment.

Similarly, the search for print materials proved less useful than was initially anticipated. There was very little information specific to cervical cancer as most information was generic and nonspecific to type of cancer. This was problematic but really emphasized the homogeneity of the approach to care at the clinic. While there was a lot of information about local resources and pamphlets for the Canadian Cancer Society, nothing was gender or cancer specific. That said, the information for the Canadian Cancer Society would certainly lead all participants to a website with a wide variety of materials. This however does preclude numerous people from Northern and remote areas as well as those who are unable to afford a computer from accessing this information. In short, the lack of print information was disappointing which resulted in its minimal impact in the research findings.

Analysis

The analysis process was an opportunity to work closely with the data, and as Kirby & Mckenna (1989:128) state, it is a chance to:

> live with the data, to get comfortable with what it has to say and to discover the 'larger more holistic understanding. The focus is on seeing patterns/arrangements...behind the totality of what's being studied' (Carney, 1983:58).

The analysis process began by listening to each audiotape from start to finish and then working through the transcription. This was no doubt living with the data. The process took endless hours, but allowed a closeness to the narratives and subsequent research

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findings that could not have been achieved if it had been outsourced. Transcription was the longest part of the analysis, but it allowed me to identify themes and to begin thematic analysis.

The primary technique of analysis was content analysis, described by Patton as "any qualitative data reduction and sense-making effort that take a volume of qualitative material and attempts to identify core consistencies and meanings" (2002, p.453). The ongoing process of content analysis relied on the competency called pattern recognition which is "the ability to see patterns in seemingly random information" (Boyatzis, 1998, p.7). Through the transcription of the 9 interviews and their subsequent re-readings, I was conscious of the need to identify, match and contrast themes throughout. Making sense of the core concepts and identifying the major themes was not a process separate from transcription; rather it was a collective and continuous process.

As thematic patterns were identified, markings were made on the transcribed interviews. Some passages demonstrated more than one theme and so these were coded as both. Boyatzis states that if "sensing a pattern or 'occurrence' can be called seeing, then the encoding of it can be called seeing as" (1998, p.4). This means that during the first thematic reading I identified what was important and during the second, and subsequent readings I identified why this was important and how this linked back to the other themes.

Once the main themes were identified, I went back to the initial literature review. The main themes and patterns that emerged linked back to the initial review of the literature in meaningful ways. From this point I began to analyze passages specifically and to link them back to the data section to which they spoke. Generally, the over-arching theme of medicalization was most prominent and came through as dominant in most interviews.

Research Limitations

Before the presentation of data, it is important to share the limitations of this research. A limitation, as defined by Creswell, is anything which will create a potential weakness of the study (2003). Similarly, Patton states "When interpreting findings, then, it becomes important to reconsider how design constraints may have affected the data available for analysis" (2002. p.562). Patton goes on to say that findings in qualitative research are highly context-based and therefore dependent on the case. While I state at the outset of the research that the case-study method limits the generalizability of the findings, I want to again emphasize methodological limitations.

The first limitation mentioned previously refers to interviewee recruitment and level of involvement. One possible, but arguably unavoidable limitation concerns the fact that owing to legal and ethical concerns, the clinic director had to approve the participation of the clinic personnel. This may have affected the demeanor of participants in so far as if they participated only owing to the request of a superior, they may not have been sincerely interested or comfortable with participation.

The second limitation refers to the location of participant interviews. By necessity, the interviews took place at the clinic, some in private offices and others in unused patient care areas. Participants were technically working at the time of the interview and therefore their responses may have been restricted to what they thought was the appropriate or correct answer to a question rather than what they 'felt'. While informed consent and protection of identity were fully discussed with the participant, there may have been anxiety regarding possible negative consequences if interviewees said something that reflected poorly on the clinic. There were some participants who seemed

so guarded in their responses that they had difficulty answering questions. Whether this was politically-informed anxiety or merely of a personal nature I am not sure, but it needs to be noted here.

While the sample size of 9 from an eligible population of 15 personnel was adequate to achieve thematic saturation, a case study typically attempts to interview everyone at the site. Of the 7 persons who declined to be interviewed, most worked in the area of pharmacy. This unfortunately limits research findings because such personnel typically instruct women receiving chemotherapy.

An additional perceived limitation was the choice not to interview women themselves but rather to interview their care providers. While Smith's (2005) work emphasizes the need to take into account the voices of women and then move to the institutional settings for their perspective, this was not deemed suitable given both the scale and primary goal of the research to assess treatment approaches. Even more importantly, while the participation of women diagnosed with cervical cancer was considered early on in the planning of this research project, for ethical reasons their involvement was excluded. Given that the central research question involves policy and in essence, practices at the clinic, the healthcare workers were deemed a more suitable choice for interviewees.

A final limitation refers to me as the researcher. This was my first venture into qualitative research; I had never interviewed people for the purpose of data collection. The first couple of interviews were difficult, and I can not say that my unfamiliarity with the process did not affect the outcome of the research. Secondly, I am myself a registered nurse. While I disclosed this to participants mostly to open up conversation I think at times they made assumptions about the level of knowledge I held - therefore I often had

to ask for clarification when participants reverted to over-medicalized language. This was a draw back, but given the chance to do it again I would do it all the same. I think being a registered nurse is a detail that was better included in the research as it is part of who I am as a researcher. While feminism does not subscribe to any particular 'method', I think many feminist researchers would appreciate the importance of disclosing personal positions of bias or value. Letherby (2000) emphasizes that this is one of the hallmarks of feminist research. In addition, while participants did often speak in medicalized terms I can not rule out the possibility that they spoke this way because they thought it was what I wanted and because I would understand it.

In any case, these are the limitations of the research. I disclose them early on to frame research findings with full disclosure of the methodological strengths and weaknesses of the project.

Reflexivity

The practice of reflexivity, according to Letherby (2003) is central to feminist research. As Allen (2004) notes, while reflexivity is not a particularly well-defined concept, it does emphasize how the researcher's personal, professional and biographical data can influence research outcomes (p.15). Perhaps the most important part of the practice of reflexivity is the transparency and disclosure on the part of the writer to make the reader aware of any potential biases or responses to the research. In keeping with this, the following passages explore the impact of my own biography on the research.

My personal experiences as a young woman being screened for cervical cancer certainly do impact my view of the research. That is, as a person who has been screened and treated at clinics and cancer centers in various provinces, I was curious about how

healthcare workers in cancer care viewed their roles. The quality of the experiences I have had while being screened vary according to the degree to which I felt informed as a patient on those occasions, as well as the perceived comfort of the healthcare workers with the subject of cervical screening and cervical cancer. This project probably arose mostly out of my interest in healthcare workers' roles and how this affects the screening and treatment process.

I am myself a Registered Nurse (RN), a fact I disclose to interviewees mainly for the purpose of transparency. However, my role as an RN does arguably raise concerns and questions about insider/outside relations. I certainly felt that I was being spoken to as an insider at times, especially in regards to medical jargon. While the insider status is often seen as useful in research settings, I feel in this situation it may have encouraged participants to medicalize their language, or tell me things they thought I wanted hear. For instance, if I had not been someone with medical knowledge, I may have elicited less medically verbose responses. However, if I was not a RN I anticipate that I would have had much greater difficulty accessing both the clinic and its staff. Despite the fact that I am a nurse, I have never worked in the area of cancer care and therefore my understanding of cancer and cancer treatment is fairly general. Arguably there are many people who have undergone cancer treatment who know more about the drugs and treatment than I. That being said, the insider status provided by my RN designation facilitated access to the facility which most likely would not be extended to other researchers.

Overall, I do feel that my personal and professional locations affect the outcomes of the research. In some instances the outcome was positive, as in the case of being granted permission from the clinic director to conduct research not only with staff but in

the physical space of the clinic on staff time. However, arguably my RN designation did result in interviewees using over-medicalized answers to non-medical questions, my role as RN possibly

Conclusion

This chapter highlighted the methodological approach adopted by this project which draws from the case-study method as well as from IE as developed by Dorothy Smith. Research techniques include individual interviews using a semi-structured research instrument followed by a thematic content analysis of policy documents to assess the functioning of the clinic with respect to cervical cancer treatment.

In the following chapter, the comments of the individuals should be taken to represent an institutional collective, rather than a series of individuals. As advocated by Dorothy Smith, this provides insight into negotiating the collective as the sum of its parts. Similarly, assessing treatment approaches as the sum of involvement of professionals in a plethora of roles aids in what Smith refers to as "a means of checking out what she or he has learned from others as she or he discovers how the persons positioned next in a sequence picks up and builds on what has been done in the previous stage" (Smith, 2005).

III Analysis: Speaking to the Literature

Data analysis was guided by the tracking of prevalent themes as identified by most or all of the participants and relating them back to the core concepts discussed in the literature review. Given the range of education and work experience, it was apparent that while some respondents are trained in the same discipline, they are positioned at different levels in the medical hierarchy. Thus comparisons could be made between those from the same medical profession who work one-on-one with patients and those who oversee and administer these roles. Also, it should be noted that all participants work in multiples areas of cancer treatment, meaning that none of the staff interviewed exclusively work with cervical cancer. This is the case with all staff at the clinic, and therefore staff must be able to 'switch gears' to work with all matter of clients. Generally, staff are focused to a site; for example the licensed practical nurse works exclusively with gynecologic cancers, as do the three physicians interviewed.

Overall, research findings point to the virtual absence of a women's health approach in current client care at the clinic. While women-centered health approaches are lacking, data analysis also demonstrates that the clinic staff are open to the possibility of learning more about this approach and possibly implementing it. Given the over-arching themes of lack of women's health approach coupled with receptivity toward the concept, subsequent research findings are best presented as the identified barriers in current practice. There also exists the potential for a positive relationship between biomedical principals and principals which are the foundation of a women's health approach. This is evidenced by the desire not to radically change medical treatment, but instead to change the way in which women are holistically viewed within the treatment setting.

Institutional barriers to implementing women's centered care can thus be identified from data analysis as: policy problems, power issues, politicizing health needs, medicalization, and understanding women's health.

Policy Problems

Misunderstandings concerning clinic policy and/or lack of continuity in the way policy was perceived and framed were prevalent throughout the interviews. This was seen across roles, from department head to director, as well as among physicians, social workers and nurses. The policy problems in evidence could generally be attributed to an unclear definition of clinic policy and lack of information regarding what constitutes a women's health approach. Participants lack of clarity in the way policy was defined made it difficult for participants to describe their role in it. Often times I resorted to asking participants how they defined policy in order to assess their involvement in it.

The unclear definitions of policy were, as mentioned above a common theme across the disciplines at the clinic. Each interview began with the policy section of questions (see Appendix 1) which asked about the interviewee's direct involvement in policy formation and application. Knowing that all personnel in the clinic are involved in policy through practice at the facility, the lack of clarity from respondents was startling.

For example, one participant was quite resistant to the idea that her job involved the interpretation and implementation of policy. She seemed to view practice and treatment policy as restricted to the independent practitioner. In regards to questions of policy, Bernice, a psychosocial oncologist, stated:

> *Umm, well I think you need them, you need to have guidelines and structure, we are all pretty independent practitioners though, and I think we need to be allowed a certain amount of flexibility in the work that we*

do…Simply because we work with clients and patients and we are kind of working off of their needs so policies are good in one respect… as long as they don't limit you in your work.

Kelly, a Licensed Practical Nurse (LPN) stated that she was not involved in policy, and when asked what policy was she seemed unsure. She also referred to policy as a singular entity. I wondered if her lack of clarity in defining policy was due to her lack of involvement in creating it. She states:

It means standards. How should I put this, when they [women] do come to the center, there are certain things we require from them and certain things they require from us.

An exclusive focus on medical treatment policy was also a common finding among the interviews. That is, when asked what part of policy the interviewee was involved in he/she would refer strictly tomedical treatment policy. For example, in the treatment of Condition A, the policy is to do Medical Treatment XYZ. This exclusive focus on medical policy left me wondering whether or where women are included in the policy. Other participants identified a delineation in the types of policies, which was reassuring, but a significant number medicalized a very non-medical question.

Elizabeth, an RN and the head of the practice area had a very similar view of policy as a medical necessity rather than a way to ensure a woman-centered or sensitive approach. For Elizabeth, the term policy suggested the following:

Yes, as far as policy goes for treatment guidelines- we have meetings and those are usually interdisciplinary and usually I am invited or one of the nurses who works with that site and we are invited to help with the development of treatment guidelines. For different types of cancer- like if it was ovarian- they would say that these are the first line approaches, second line- same with cervical. Policy development, sometime there are different ways of giving treatment and we are giving it a different way [interruption]. So there might be a different way of giving the medications and whether we want to try giving that- it is done collaboratively

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Front-line professionals seemed to have the least secure grasp on general policy versus treatment policy. Megan, a radiation therapist who works one to one with patients daily, had quite candid thoughts on what policy was, was not, and what it should be.

> *A lot of the policies that we see are very dry and boring. Um sometimes the policy that pertains to us there does not seem to be a lot of it, the very general stuff. It is the policy stuff that we would more use every day...if we had as you were saying a policy on women's health that would help us every day- who to contact and where that information is and how to proceed through that- that is something we would be looking at all of the time. I think sometimes policies are made by politicians (laugh) as opposed to the front-line people...And policy is, I guess we need to be defining it more clearly and what our role is within the policy or the procedure and how they fit together. Because I think we are more involved in the procedure type and the policy type things come from above and we need to feel that they are coming from us.*

To her credit, Megan acknowledges her lack of knowledge, and adds on that she would be willing to get involved in policy development to facilitate getting through 'every day' as she says. This type of statement emphasizes that while the clinic may not yet have the policies they need in place, they have the capacity to make the necessary changes, which is a large part of the battle.

Patient input/Women centered policy (PI).

One of the most important foci of this research involves determining the degree to which women patients at the clinic are incorporated into the policy-making process. This was addressed by first asking the clinic personnel if he/she felt that the clinic used a women's health approach, and then whether women with cancer or survivors of cancer were involved in policy making. As with most other questions, the interviewee responses varied.

Alice, a participant who had a gynecology practice and is involved in making policy was asked about the involvement of women in the policy making process:

Not with cervix, to date...Sometimes what they say in clinic follow-up will influence how we write the policy, so it is not formally access to policy...

With respect to involving women in policy and women's potential reluctance to participate due to the sensitivity issues, Alice thought that this was no longer an issue among younger persons. Alice emphasized that young women have been brought into a very open program- through the cancer prevention program, which does take into account women's health needs. Alice explains:

We send out the birthday letter at 18, and I don't know whether or not that works. I think it does from casual conversations with colleagues whose daughters have received their purple letter- their birthday letter. Um there is a lot less angst in the younger generation to talk about and to access care for women for women things. Whether it be pap smears or contraception.... And I think that that attitude is a healthy attitude and I think the screening program has promoted that attitude, but is that attitude only in the middle class, I don't know. I don't have a lot of chance to talk to people in the lower class, the impoverished, the socioeconomic deprived.

The birthday letter Alice is talking about is a letter from the Cancer Agency, which is distributed to all women in the province of Saskatchewan when they turn eighteen. The letter campaign was initiated as an additional tool to inform women of their need to begin cervical screening at the age of 18.

Regarding the birthday letter, Alice emphasizes an important point. While the daughters of her colleagues may have demonstrated positive attitudes about the program, they represent a small percentage of the women targeted. Arguably, a thorough evaluation and analysis of the program on the basis of the socioeconomic background, ethnicity, etc. of the targeted women is warranted. This is an important first step in making the program more women- centered.

Elizabeth, a registered nurse, identifies some of the stressors facing women who have cervical cancer treatment.

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I am thinking [there needs to be]*something more on the counseling side that might meet your needs, but yeah, I am not sure- but I guess in order to find out you could do some sort of survey with these sorts of individuals to find out...*[women'sspecific needs are]*family, caregiver role, whether it is children or spouses- that would be a big one. What else, a lot of women are working too, a lot of single women ...a lot of women are providing financially for their families too, right? And I think they tend to be from a single family and they are the breadwinner, so that would be a big winner.*

Elizabeth thus points out some of the very traditional and non-traditional stressors facing women's having cervical cancer treatment. She also identifies target areas to improve care.

I think maybe- Oh geez, more on patient education piece. I would like to see that improved or at least see resources there. Umm the support groups, although I am thinking there is something out there for them already, but that would be another area. I think those would be the two big ones.

Alice also identified the individual needs of those with cervical cancer.

... each subset of patients actually[has specific needs] *and yet women definitely...with cervical, because it is an area that people are not generally comfortable talking about- people are not generally comfortable talking about sexual health they don't like to discuss with our partners what they need to change and partners need to be educated that it is still ok to be involved, that there are alternatives and I don't- I mean we have books around, for the patients, I know the nurses do some our umm nurses upstairs do some teaching, but umm you know most people say well the surgeons should be talking to them, and the surgeon says, well so and so and you know, no one really wants to take it upon themselves. And it could be life changing lots of times for women- even the surgery, like the hysterectomy if you have to have everything taken out it can be really hard for people-*

Regarding patients' involvement in policy making through evaluation of services and committees, some participants seemed to think this was out of the ordinary. Andrea, a radiation therapist, hypothesizes that patients are more concerned with getting their treatment and would never question the way in which it takes place.

...most patients come in and are not worried about that stuff they come in and want to be treated correctly they don't know what happens under that, like policy, they are just worried about the treatment and managing the disease. There is probably a subset of patients who do know about policy and are concerned about that, but not very many.

The sentiment expressed by this participant is very interesting. While some interviewees expressed an eager interest in getting patients involved in policy making and thus altering thepolicy development format, this participant denies that they would have any interest in involvement in policy at the clinic. On one hand, this response cultivates a medical paternalism that minimizes patients' concerns, emphasizing that clients are more interested in getting their treatment and getting out of the clinic. Andrea also indicates that patients are not concerned with what is going on in the clinic, and due to the lack of evaluation of clients attending the clinic this may be somewhat dismissive of clients' needs. In general though, this comment does emphasize the need for more investigation into what women receiving treatment truly want, rather than continued speculation. The foundations of a women's health approach certainly emphasize the importance of women being involved in medical decision making, regardless of the level.

Megan, a radiation therapist remarked that patients were evaluated from time to time for the benefit of improving service provision. She says:

We do survey from time to time, I would not be able to tell you what the results are, but for the main part we never have any problems. I am going to credit my staff with that, they bend over backwards to make clients happy...the most recent ones were relating to the hours of operation, I guess it was the Stats dept that was looking at it. A couple of years ago we were looking at how the service was and again we asked the IM division, and I don't know what that would be now, but there are groups who are working for the agency that do put statistics together and help to post the appropriate questions.

Andrew, a gynecologic oncologist, expressed discontentment with the lack of women's health awareness that is incorporated into care at the clinic.

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My impression has been... in healthcare in general, women's healthcare sometimes takes second place to other healthcare priorities. Now within women's healthcare there seem to be certain diseases that seem to take higher priority. For example, breast cancer has taken priority over a lot of other issues, but that's good- because we need that. So I guess the original question was, what do I feel about the policies already in place- I think that there needs to be more emphasis on awareness and that includes all the cancer, cervical cancer, ovarian cancer, all the gyne cancers. One reason that maybe the priority is less than it should be is because these are diseases that are relatively rare, compared to say breast cancer and they are relatively less glamorous to manage and treat than coronary artery disease. But they are there and the most devastating thing about them, especially the cervical cancer and ovarian cancer, because although very rare, most women who get ovarian and cervical cancer still die of it. Umm, so unfortunately it is devastating that we do not put more emphasis on treating these diseases or catching them at an early stage...these diseases are affecting women during their reproductive years when they are active in society and employment and it is devastating to families. It is very important that we promote things like HPV vaccines or other components to cervical cancer screening. Or promote awareness about ovarian cancer.

What is particularly significant about Andrew's comments is that he has been working at the clinic the least amount of time and seems to be the most discontent with the way things are conducted at the cancer clinic. He rightly raises the point that breast cancer attracts more public attention, and that more awareness needs to be raised in respect to cervical cancer, but he doesn't really offer any suggestions as to how it should be done. What he does mention is the severity of the cervical and ovarian cancer - women often die because the disease is so progressed by the time they receive treatment. He also raises the issue of how important it is to treat women in their reproductive years but does not elaborate on how we could attend to these unique needs.

Two participants mentioned that there was a 'lay advisory' committee which accessed survivors of cancer, people living with cancer and people from the community to help circulate ideas regarding treatment and policy. Beverly, a psychosocial oncologist describes this:

There are lay advisors and when there are things, they are not so much involved in the policies that affect staff behaviours, those are more procedural, because we have legislation that dictates a lot of that. But in terms of just the clinic and how we do things here, bringing concerns forward and those things influence policy and process so in that way they really influence.

The lay advisory committees, which seem to be in the early stages of incorporation, are a step toward patient involvement. Having only two of the nine participants mention this means that more awareness needs to be raised in order to direct patients to this service.

Power Issues

One recurrent theme among the research findings was that of power differentials. Participants felt disempowered and often deferred to their superiors when discussing policy roles, and also on other occasions. The main target of the critique was the physician's role. That is, physicians were most often deferred to as the 'policy makers' but participants also identified them as not adhering to policies. I refer to this as physician role critique (PRC). When it came to an apparent power dynamic, it always seemed a physician was implicated by the interviewees.

When discussing the development of policies, and who creates them, Megan (RT) identified that although other persons in the clinic had superior knowledge, the physicians

were the gatekeepers in the policy making process. She states:

Well, it depends what it is for- certainly any written information that we hand to the patient, so just the education would go through the physicians first, just to make sure we are not telling them something they do not like. Because we tend to be more on top of the latest things than they do, so it is trying to get them to move with the times and sometimes they will and sometimes they don't. How regularly they want us to take images to ensure that we are right smack in place, they would be in the policies but then the technique as to how we acquire those images [radiological images] would not be included in that.

In contrast, Elizabeth, (R.N.) did not indicate that she had a problem with physicians as gatekeepers, but did indicate a problem with how information is passed on to them for their approval and subsequent policy change. Elizabeth explains:

Basically we do general education with the staff- so I would do a talk about the nursing side- I find it interesting because when we have a new policy come out in general at the cancer agency that I would take it to my staff and pharmacy to theirs, but I find that the physicians do not see it as their responsibility to tell their colleagues about it- and we will be in our meetings and someone will say- 'well who is going to talk to the doctors about that?' – and I think, well that would be your job! Because you are the head of medical oncology or you are the head of radiation oncology, but they do not see themselves in that role, which is kind of interesting.

Bernice, a member of psychosocial services, indicated a problem with attaining appropriate referrals to her unit from physicians. While physician respondents emphasized the importance of psychosocial services this one participant did not feel that was always the case.

I think psychosocial services are being more recognized as a part of medical treatment certainly there is a big change in that from when I first started. We get called in on difficult cases or situations more often than we ever used to. And I think people have learned that what we can do is very helpful to help them adjust and cope with what they are going through...getting medical staff to refer to us appropriately and more timely is always going to be an issue but it is certainly better than it was 2 years ago.

Alice, (physician) while held in high esteem by her colleagues seemed to express a serious sense of disempowerment, despite her very central position in policy making.

> *I have very little role in healthcare policy, um I sit on the cervical cancer screening program quality assurance and one of the other sub-committees. I sit as the chair of the gyne-oncology group...I sit on the SMA [Saskatchewan Medical Association], but really I have not been able to do a lot with policy. No...just no power. No time.*

This quote by Alice seems to express a certain sentiment of powerlessness. While Alice holds an important position she seems not to have the ability to affect much change. Because Alice is in a 'higher' position and she seems to express disengagement with the policy process it may explain why participants with less power are significantly more disengaged.

Politicizing

Another theme that came up in nearly every participant interview was the issue of patient wait times. While this is a major political issue, it was surprising how often it was incorporated into the answers to the interview questions. The way in which these responses were spontaneously inserted indicated a certain amount of politicization of cancer treatment. The new Federal government[10] made waiting times one of their five priorities in the last federal election and indicated that cancer treatment was one of their central foci. This seepage of political agenda into a healthcare setting was worrisome, because it seems to largely favor quantity of treatment rather than quality. This is not to dismiss the concerns of waiting, certainly waiting can be a very cruel and painful process.

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[10] A new federal Conservative government was elected February 6th, 2006, led Prime Minister Stephen Harper.

But the great focus on 'wait times' seems to be an oversimplification of what maybe greater concerns. Kelly, an LPN, emphasized the concerns regarding wait times.

I would change the layout, bigger rooms, space basically. I would change to no wait list, no wait times. Have the opportunity to come in as soon as they are diagnosed. I just feel that the waiting times has to be devastating and knowing they have the cancer and knowing there is a wait list and they know they won't be in for a while and just for them to have that chance to get into treatment or if they are palliative for pain management, I guess just look out for their needs.

Elizabeth (R.N.) echoed these sentiments by adding:

I think on the treatment side it would be the timeliness of it, so the first part of it would be because we are a referral based system, so insuring that referral is coming in on a timely basis... timely access to an oncologist- we are fortunate here to have a gyne-oncologist. Before we did not have someone to see these cancer specialties, so they were basically put in the queue with the other 150 patients waiting, unless it was deemed urgent, if it was a curative type, [if it was considered curable it was considered urgent] and a lot of them weren't then they get put in the queue.

While it is challenging to predict the exact implications of politicization, surely there is an impact on practice when patients are only heard to be saying, treat me faster, and seemingly have few other concerns.

Medicalizing

A theme that arose quite expectedly from the data was that of medicalization, although it did so in an unanticipated manner. Medicalized language emerged time and time again in responses when participants didn't really know what else to say, or how to respond to human-centered questions. Participants would take a question that seemed to be a pretty straight forward person-centered question and instead of applying their thoughts or impressions, they would apply medical language and practice.

For example, when Megan (RT) was asked about the change in the patient population, she changed the subject and started talking about a very technical aspect of

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treatment. I found this to be quite a common occurrence - to revert to medical speak as a

way to avoid the central issue. Megan illustrates:

> *I don't believe there has been a lot of change in numbers we have seen, I think it has been fairly steady, maybe slightly younger, To be honest, its probably one of the areas that has not changed a whole lot. For you know the type of cases that come in, the types of cases we see. I certainly don't think there has been a change. There are certainly more surgeries being done which means we don't have to use our brachiatherapy unit. Now I am not sure how much you know about the selectron unit or the HDR unit. If a patient has not had a hysterectomy, the uterus is an excellent organ to be able to insert catheters into to allow us to give a higher dose to that actual organ and the selectron or the HDR unit- they have one in Regina and we have a selectron unit- which is a micro and it actually puts slow sources of sethium (?) directly into using a uterine tube, and you place that right into the uterus so you can get higher doses of radiation throughout the uterus and then there is also ovoids that go into the base of the cervix and this allows us to give a higher dose of radiation to the cervix, rather than treating the whole pelvis, where with the external beam treatment you would be treating from the front and the back and the sides, but we want to take in the nodes, so we have to treat the whole pelvis.*

As this quote demonstrates, instead of talking about the actual people - the clients she

sees, Megan describes in detail the treatment for the condition. This was a fairly common

occurrence, which made follow-up questions necessary in order to get the human-

centered question answered.

Andrea, a radiation therapist gave a very similar response to the same question:

> *...our clients, in regards to cervical cancer are patients who have been diagnosed and the radiation is used as a complementary treatment to chemo or surgery or advent or it could be the sole treatment depending on the stage of the cancer- but most often it is an advent treatment. With surgery and chemo, and in the late stages it could be treatment for pain and control.*

To illustrate further, the following quote demonstrates an answer to a question

asked of all participants referring to big picture feedback regarding treatment. This

participant, along with several others, focused instead on the follow-up for physical

manifestations of the illness, rather than the emotional baggage that is inevitably tied up in it. Below is Elizabeth's response to this question.

> *Well, we do follow up especially when they are getting the first treatment and we will call them a couple of days after the first treatment, not to be too narrow but to see if there are any side effects- as far as nausea and vomiting, and there is a follow-up phone call and checkup with them and then there is a lot of stuff related to side effects.*

(Mis)Understanding Women's Health

A lack of understanding of a women's health approach was one of the most prominent research findings. No interviewee could define it or outline what it might entail. Interviewees were asked the questions: 'do you feel the program is designed for women with women in mind' and 'what are women's specific needs? The responses fell into two categories; the first focused on women's need to have adequate access to information and the other response was generally a vague response as to what they thought might be women's needs. The two questions were followed by directly asking interviewees if they could define a women's health approach, which no one could.

The following collection of quotes illustrates the vague responses of interviewees when asked about a women's health approach:

> *Beverly (psychosocial oncology) - We don't always hear about it but I am assuming for every woman who comes to have radiation in that area will have issues you know and we don't address it formally and because we are quite resource scarce with our staff and it is only part-time staff for the gyne patients but it is just something that is not addressed formally. So it is definitely a lack[of services].*

> *Elizabeth (RN)- You know, I am not sure ... if we have any support groups specific to it- the psychosocial oncology group has a lot of support groups that they put on, so some are in the day some are in the evening- I am not sure if there is any group specific to gyne cancers. You would have to speak to ...psychosocial oncology and they do hold a number of different groups, so they may hold a number of different groups like- lung, or breast cancer support and they would help to facilitate discussion with. Other than that I am not sure that there is.*

> *Bernice (Psychosocial Oncology)- Umm, probably there is more of that in breast cancer- women's health, I mean certainly with the women's health center here in Saskatoon and umm not anything to our cancer clinic here though. We have always had a support group for women with breast cancer support group, metastatic breast cancer support group over the years so there has always been that sort of thing.*

This collection of quotes demonstrates that the participants were eager to search for a women's health approach in their work, but were hard pressed to find it. Their tacitrecognition of the importance of a women's health approach is definitely an asset and is certainly the starting place for developing women-centered policy.

The Women and What They Need

Many interviewees were candid in their descriptions of the women treated for cervical cancer, which was useful in anticipating the difficulties in delivering treatment. Many times the participants told of patients traveling great distances to access treatment and of patient living conditions that created barriers for treatment. The purpose of discussing this theme was to explore the extent to which their policies ad practices use a women's health approach.

The most recent study examining the difference in infection rates of cervical cancer between native and non-native persons in Saskatchewan dates from 1990. This study demonstrated that the rate of infection for Aboriginal women is nearly 10 times the non-aboriginal rate (Gillis, Irvine, Tan, Liu, Robson, 1990). Many interviewees thus described the possible challenges that aboriginal persons face in seeking treatment.

As one participant described it, the populations which are ghettoized face much greater challenges. Few of the respondents were as attuned to the socio-economic challenges faced as one of the gynecologic oncologists, Alice.

I would say that our demographics follow the British Columbia study which show that people who don't access pap smears are people for whom English or French is not their first language, and it also falls on those people who live in a ghetto type situation, whether it be a Sikh population in Surrey, or a Chinese population in Chinatown in Vancouver. For us it is definitely the people who live on reserves or live in the city in reserve type populations. Our Native American people are very underserved. I would say just off the top of my head that easily half of my patients are native who have cervical cancer.

Beverly, a psychosocial oncologist, also emphasized the difficulties people from the North face

in getting to their treatment:

Yes. It is hard to get down here for treatment, because a lot of women from the northern communities also have families. The one thing that is interesting, is that many women are still their family care-givers, so for them to have treatment and to be out of commission while in that role is difficult and we don't see that with men with prostate cancer...And it is very difficult for people in the far north because they have to travel to get down here, be away from their support system back home depending on whether they are going to have radiation or chemo, or both or even surgery. So that is very hard for people who live a great distance away. As well as funding for people when they need to be here for long periods of time and they need places to stay, they need accommodations, meals, travel and all of that is difficult.

The following response from Andrea (RT) illustrates the completely different

lifestyle characterizing the North that is not and perhaps can not be addressed by the

current screening program.

So the challenges were, I guess you are dealing with cancer, so right away when you say the word, it brings forward a lot of emotions with people and their families. SO that can be a challenge in itself. That side of it and the patient care side of it, dealing with the patient care side of it. And specifically with cervical if we are dealing with the northern residents, they are far away. Lots of them don't have telephones, so the challenges of getting them here and compliant with these appointments... if they can be sometimes people who aren't compliant with other areas of their care, then they might not be compliant in coming to see us. Once you get people here though they are usually pretty good.

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In contrast, Andrew, a gynecologic oncologist, expresses a certain amount of trepidation in answering this question, although what he is saying is that First Nations' women are presenting more commonly with cervical cancer and they are screened less often.

> *One issue is that cervical cancer is presenting here at a more advanced stage and that speaks to our screening program and I suspect that there are certain members of the population that are not getting screened as regularly as recommended, and, there is data to show that first nations women have higher rates of cervical cancer than the rest of the population of Saskatchewan... that is data specific to Saskatchewan. So that would be one population group or component of the population that I think we need to address.*

Another theme that came through in every participant interview was the need for more patient education in order to enhance screening and decrease incidence, but also to enhance the treatment experience. That is, if women are provided with adequate information they may be better able to cope with the coming months of treatment. The following quotes demonstrate the need for more education:

> *Andrew (Gynecologist Oncologist)--Getting patients more involved and better educated with things like HPV, and the vaccine, and looking more toward the barriers and screening, getting people with the cancer into the clinics sooner.*

> *Elizabeth (RN)-... one of the biggest things for the client is just to be given information so even if we have a patient who is palliative, that probably isn't going to get any treatment, they need to be seen by a doctor to be told that. I hear it time and time again from new patients- they need to have that visit, so it depends on what is the cancer and what is the prognosis. Are there any options there for them... and they really need that information and they feel they really can not move on until they get that information.*

This emphasis on education does have some implications for a women's health approach. That is, what both Andrew and Elizabeth emphasized is more education, which helps women make informed decisions about screening, treatment and lifestyle. This is central

to an understanding of a women's health approach, and even though they do not characterize it as such, it certainly can be seen to be an example of women centered care.

Print material

The print data accessed for the purpose of this research was provided by the cancer clinic. It was analyzed as a way to compare what the staff at the clinic said with what they are distributing to women receiving treatment. In short, the interviews with clinic staff overwhelmingly indicate that a women's health approach is absent and the pamphlets and other print material distributed to women receiving treatment largely echo this same research finding. The print information takes the form of a pre-made package prepared for people with all types of cancer attending the clinic, and it is provided to all new clinic attendees. While the print material is specific to the clinic, it is not specific to the type of cancer or gender of the client.

The homogeneity of the print information is noteworthy because it is reflective of the way in which the patients are viewed. That is, the interviews reveal that healthcare workers' interactions with women do not take into account the specific concerns of women's health and the homogeneity of the print material reinforces this approach. However, while the package does focus on the medicalized aspects of cancer treatment it also provides referral information for psychosocial services. Also, the print material identifies some challenges that a person with cancer might have and how to address those issues. The package also includes the business card of a psychosocial oncologist in charge of patient access services. This person's contact information is provided so that questions clients have before, after or during treatment can be answered.

In addition to the clinic-specific information, the print material also contains information from the Canadian Cancer Society. This information, while general, does

provide referral to the website where more specific information can be accessed. Again, clients having unlimited access to this information does provide a sense of control over one's own health, but the material is in this case, gender neutral and non-cancer specific. That is, there is absolutely no mention or indication in the print material of women's health issues, or a women's health approach to the treatment of cervical cancer.

Thus, while the review of the print information revealed little new information, it served to reinforce the analysis of the interviews as reflecting client care that does not attend to women's specific health issues.

Conclusion

This chapter presented research findings in the form of the prevalent themes gleaned from individual interviews with medical staff as well as from the print material distributed to patients at the clinic. These themes included:

1. policy problems

2. power issues

3. politicizing health needs

4. medicalization

5. (mis)understandings of women's health.

The themes listed above form the basis for the discussion provided in the next chapter.

IV Discussion of Barriers

The following section will provide a discussion of the barriers to implementation of a women-centered health approach that were presented in the previous chapter.

Medicalizing

Participants in this case study represent a range of healthcare professions. Some have greater than ten years of post-secondary education and many years of work experience, while others practice under practical diplomas and degrees and/or have much less work experience. Despite the dissimilarity in degree of formal education and work experience all provide care and health services for patients in the clinic diagnosed with cervical cancer (and other cancers) and tend to revert to medicalized language when discussing aspects of client care. Thus the prevalence of medicalization can be viewed as a major barrier to a successful implementation of a women's health approach.

Throughout this thesis, medicalization has been defined to mean that conditions and behaviors are given medical meaning and understood through the lens of health and illness and second, that medical practice is seen as the responsible institution for the elimination of said conditions and behaviors (Kohler Riessman, 1998). This definition sees the process of medicalization taking place at the conceptual level, where medical jargon is used to define the problem institutionally, and where the medical institution legitimizes programs for mitigating a problem and finally through doctor - patient interaction. While this definition rightly encompasses the many venues for medicalization at the institutional level, research findings from this study shows how this manifests at an interpersonal level and well beyond the doctor-patient relationship.

While the participants in the research were somewhat represented by physicians, the ability to revert to medical speak, and to medicalize interactions with patients crossed the boundaries of level and extent of medical training. Kohler Reissman (1998) agrees that the doctor-patient relationship is one of the anticipated venues for medicalization, and that the tendency to medicalize goes beyond physicians. Research findings from this study confirm this view in that medicalized language was employed by nurses, psychosocial oncologists, and radiation therapists. These findings suggest that medicalization is not the sole view of physicians, but is rather a general product of the greater bio-medical model which influences the overall practice of the clinic.

Medicalization, for the purpose of this study, refers to the divorce of the observation from the interpretation of scientific knowledge (Findlay, 1993). Findlay notes that earlier assertions regarding medical diagnosis and practice assumed that observation and interpretation were intricately linked, that observations could not be altered when being interpreted and that the biases and influences of the interpreter could not seep into the data. Feminist research has since inserted the importance of analyzing positivistic-type research through a critical lens, which looks at potential bias inherited through interpretation.

In regards to a clinic environment, healthcare professionals are often encouraged to maintain a veil of objectivity. Objectivity in the clinic setting is desirable for healthcare workers because of its concretes and absolutes. These provide answers that are not grey - but rather black and white. The concept of medicalization incorporates this need for objectivity and in the context of this clinic it is basically a spilling over of medical ideology and practice onto patients. Pauly Morgan notes that because medicalization is portrayed as a positive and benevolent process it tends to be more easily spread and

camouflaged – it also means that any criticism of medicalization can be seen as an attack on public health (Pauly Morgan, 1998, p.86).

As demonstrated, the research findings display an over-reliance on the use of medicalized language, not only with respect to health treatment procedures at the clinic, but also regarding patient identity. This confirms a thesis by Pauly Morgan that medicalization is pervasive and camouflaged. She classifies its camouflage as two fold: "first as a technical, scientific one that is purely objective in nature and, second, as a process done for the loftiest of altruistic and benevolent reasons" (Pauly Morgan, 1998, p.86).

Through the first veil of objectivity and secondly of good will, it is hard to imagine how negative reactions to medicalization would be taken seriously. And while the increasing presence of medicalization does have some bearing on patient care, I do not agree with the extreme assertion that "medicalization has the dangerous potential to lead to real evil" (Pauly Morgan, 1998, p.86). Clearly, medicalization should not pervade the healthcare system to the extent that clients are viewed only as medical cases. Medicalization depersonalizes and makes the person and illness one, when in fact it is the person who is being treated, not the illness. Further, if we are to follow a women's health approach it means that we must allow women to make informed decisions.

In this same light, Thomas–Maclean argues that "one unintended outcome of the modern transformation of the medical care system is that it does just about everything to drive the practitioner's attention away from the experience of illness" (Thomas-Maclean, 2000, p.45). This transformation means that the target of the treatment is the disease, rather than the illness of the suffering person. The radiation therapist who stated that "patients come in and are not worried about that stuff ... they are just worried about the

treatment and managing the disease" is closing the door on further discussion of women's health needs. It also suggests an element of paternalism which was echoed in many of the interviews.

Medicalization is therefore a major barrier not only towards implementing a women's health approach but also to basic care. Perhaps one major reason that medicalization is so pervasive is because of the lack of women's input into their treatment process and the policies of the clinic. This need for consultation, women's input and awareness will be discussed further in the following chapter.

Sorting out the Positives

The prevalence of medicalization is largely seen as a negative practice in women's health provision, but there are positive practices that must be acknowledged by this case study. According to Pauly-Morgan (1998) medicalization "will involve shared cultural practices that support the legitimacy of using medical concepts, theories, and discourses to describe medicalized life phenomena and the acceptance of medical interventions to 'treat' them" (1998, p.88). In the context of the clinic, and the cervical cancer screening program in particular, there is invaluable benefit to utilizing uniform and non-individualized approaches to screening - even though it suggests medicalization. That is, the cervical cancer screening program was launched based on research findings from the Health Services Utilization Research Commission (HSURC) (Government of Saskatchewan, 1998), whose findings indicated that women over the age of 35 were generally under-screened while women between the ages of 18 and 34 were generally over-screened.

Based on these findings the province implemented standards for screening which were aimed at decreasing the rates of cervical cancer among under-screened women.

Studies[11] have found that early screening can prevent nearly 90 percent of invasive cervical cancer, which decreases the likelihood that women will end up needing the services of cancer treatment (Ratnam, Franco, & Ferenczy, 2000; Grunfeld, 1997). The manifestation of medicalization in the form of cervical cancer screening that is minimally invasive is arguably highly beneficial for women, and thus could be viewed as positive. Many studies demonstrate that HPV causes up to 95 percent of all cervical cancer and if left untreated will cause cancer. Therefore implementing a program which is minimally invasive and seeks to decrease the need for screening when unnecessary is significantly beneficial (Dawar, Deeks & Dobson, 2007).

The question remaining is whether a healthcare system can adopt medicalization when beneficial without it becoming a pervasive feature of the practitioner-client relationship. For example, Kohler Reissman (1998) explains that one of the drawbacks of medicalization is that once women enter the realm of treatment, or in this case, the clinic, their illness is stripped of its political and social context. Thomas-Maclean (2000) also emphasizes the significance of the shift in physician focus from treating the person with the illness to treating only the disease. While there are thus positive outcomes of the medicalization process, such as universal screening programs, the negative outcomes have a potentially dehumanizing effect on the women seeking treatment.

The 2 men and 7 women interviewed for this study are all undeniably well-intentioned. While all indicated that their job was to treat cancer and they had strong convictions about the quality of treatment they provided, few talked about patients as human beings. The classification of patients as types of diseases, such as 'the breast

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[11] Research that emphasizes the importance of screening has also indicated that 50 percent of women with cancer of the cervix have never had a pap test (Grunfeld, 1997).

ladies' medicalizes women in a harmful way. In fact, it is the benevolence and good will that Pauly-Morgan warns us about. This veil of benevolence, in addition to the scientific rationale for medicalization, encourages its passage into realms of life that do not need medicaliztion - as in the case of classifying someone based on her disease rather than onthe many other distinguishing characteristics which she embodies.

Screening

The cervical cancer screening program, which aims to reduce the incidence of invasive cervical cancer, is clearly an example of the surveillance of which Foucault speaks. Saskatchewan Cancer Care uses the program to track papinicolou (pap) results and to monitor positive test results. It is through this form of formal surveillance that the incidence of invasive cervical cancer can be reduced. Research indicates that screening programs (ie: pap testing) can detect 90 percent of possible cancers and provide minor treatment (Ratnam, Franco, & Ferenczy, 2000; Grunfeld, 1997). If early detection is not in place the result is an invasive cancer. This is evidenced by the fact that rates of cervical cancer in developing nations are significantly higher than western industrialized nations with formal screening programs in place. "Central and South America, southern and eastern Africa, and the Caribbean, [have] incidence rates of at least 30 new cases per 100 000 women per year" (Franco, Duarte-Franco & Ferenczy, 2001, p.1017), whereas in Canada this number is less than 10 per 100 000 women. Success in the form of a decreased incidence of invasive cervical cancer lends itself to supporting the success of formal cervical cancer screening programs.

That formal screening programs have decreased the incidence of invasive cervical cancer is laudable, but it is equally important to reflect on the significance of it as a form

of surveillance. The concept of the panopticon, described by Foucault as an unnecessary and intrusive surveillance of human action, is clearly relevant to the clinic setting (1973).

One might assume that all women would want to avoid getting cervical cancer and would therefore capitulate to screening. In fact, many women fall through the screening cracks in part because of a perceived impingement on their agency. In the case of this clinic (consistent with national cervical cancer screening efforts), the underserved are generally Native women, whose rate of cervical cancer is nearly 6 times that of their non-native counterparts (Franco, Duarte-Franco & Ferenczy, 2001). Neilson and Jones (19988, p.573), state that surveillance, especially in the case of a targeted population "creates ambivalence between being a free agent or 'more at the mercy of biology'". In keeping with this claim, by aggressively targeting certain populations, we do impinge on self-perceived agency and autonomy. However, the success of the birthday letter has been quite successful. That is when women are sent the letter to remind them of the need for cervical screening at their homes, there has been very little, if any objection to the call for self surveillance.

When the formal cervical screening surveillance program was launched, there was at first a short-lived public backlash to women being monitored in this way. Though there was no paper trail detailing this objection, Allan (a physician) remarked

> *At the beginning of the program there were issues with privacy and there were a number of women, a very small number of women relative to all of those eligible, who objected to the cancer agency having access to the information.*

Thus, the argument in favor of self-surveillance as a means of cervical cancer monitoring was only slightly affected by the creation of an opt-out clause for women. The clause stated that an individual could choose not to be involved in the program by writing a letter

to the agency indicating her preference. It is noteworthy that the program designers had precluded the possibility that women would object to the surveillance because it was 'for her own good'. This is complementary to Pauly-Morgan's original thesis on medicalization - that benevolence is a mighty good camouflage.

The issue of surveillance per se was not raised by any interviewee, but comments regarding types of behaviors and persons who require more surveillance were prevalent. First Nations persons and people living north of the treatment center were singled out by many of the participants as comprising problem populations. Some participants indicated an obvious geographic impediment, with many First Nations people living a far distance from treatment centers. One participant noted the socioeconomic status of many First Nations and Aboriginal people living in the inner city as a ghettoized population and that those who live outside the city are sometimes isolated from care. Another participant remarked that it is difficult to retain healthcare professionals in the remote areas where many female First Nations persons reside. The inability to recruit and retain rural and remote health-care workers means that women are not able to attain adequate screening in order to detect early stages of disease.

There are other implications for First Nations and Northern women. Although not widely cited, research provides evidence regarding other barriers to treatment for Aboriginal women. One such study assessed a group of minority women in Northern Ontario. The findings indicate that 33 percent of Ojibwa and Cree women refused internal exams, compared to 0 and 8 percent among other minority groups (Steven, Fitch, Dhaliwal, Kirk-Gardner, Sevean, Jamieson & Woodbeck, 2004). Findings of this sort indicate the need for greater consultation with Aboriginal women to discuss strategies for creating and disseminating educational material.

This issue of surveillance raises several barriers for healthcare questions, primarily in the area of raising awareness, evaluation or current screening and finding ways to reach out to sensitive populations, such as the First Nations community. Recommendations towards these barriers will be discussed in the following chapter.

Needing Evaluation

Yet another barrier identified in the informant interviews involved the need for evaluation of the current program. Each candidate was asked about current evaluative strategies, but none of the participants were familiar with any. Some were aware of internal evaluations that had been done, but they were not privy to the findings, even those operating at the management level. Also, the scope of the few evaluations done was limited. One participant spoke of an evaluation to assess the current hours of operation and whether clients were satisfied with them. She too, was unaware of the research results.

Given that this thesis examines cervical cancer treatment policy through the eyes of the healthcare providers it is significant that workers were not unaware of evaluation results. One would expect that the goal of any evaluation would be to improve care and arguably this cannot be done without the inclusion of the front line and administrative healthcare workers. At the time of this research no efforts were being made to enhance the quality of care through a systematic evaluation of practice and policy.

The experiences and opinions of women clients were also not informing treatment in any way. This confirms findings of Thomas-Maclean (2000) that such settings divorce treatment of the disease from the self-perceived needs of the ill person (Thomas-Maclean, 2000). It also points to the fact that medicalization subverts resistance, or "resistance

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comes to look increasingly irrational since health - an intrinsic good - cannot reasonably be called into question" (Pauly-Morgan, 1998, p.86). The interviewees' perception of the program as doing fine without evaluation or believing that patients are not interested in involving themselves illustrates the degree to which medicalization is firmly entrenched with the clinic.

Breast versus the Rest

Breast cancer awareness and fund raising is currently comparatively high profile - its paraphernalia now covers a range of chocolate bars, pins and buttons, women's scarves and entire lines of women's clothing. Breast cancer fundraising has become a nothing short of a profitable business. While the signature soft pink color is somewhat condescending and infantile, if nothing else, this recent commercial surge has raised the profile of the disease and brought awareness to the importance of screening. In contrast, there are no cervix - shaped M & M's since cervical cancer is simply not that sexy. Moreover, cervical cancer incidence and mortality have dropped over the last three decades, while the incidence of breast cancer is on the rise. Table 2 identifies data from the National Cancer Institute of Canada (2000) that indicates incidence and mortality of breast cancer versus that of cervical cancer.

Figure 10.3
Breast and Cervix Age-Standardized Rates, by Age Group, 1970-2000
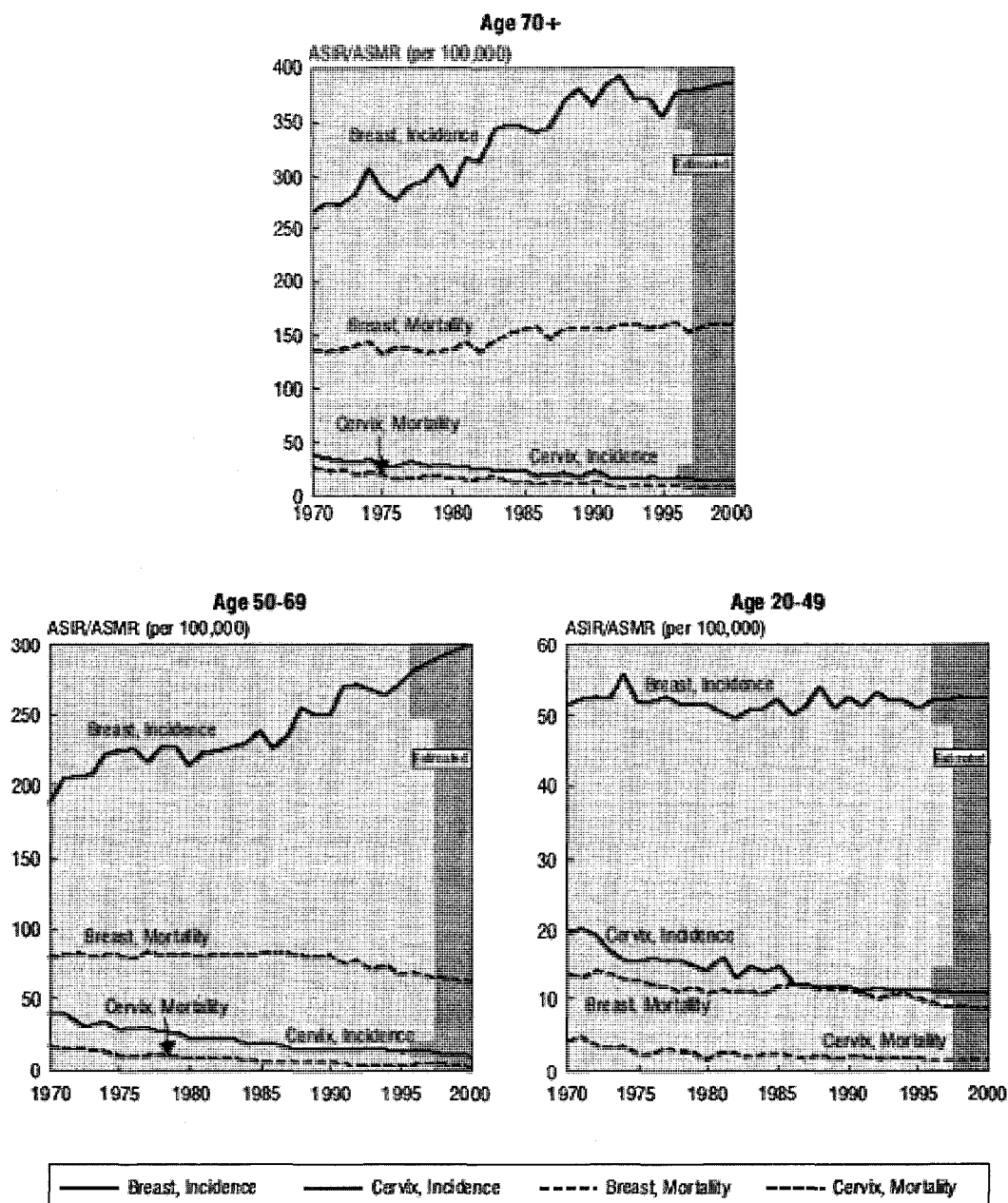
Note: Rates are standardized to the age distribution of the 1991 Canadian population.
Source: Cancer Bureau, LCDC, Health Canada

(National Cancer Institute of Canada, 2000)

Decreased incidence of cervical cancer is due largely to widespread screening programs in the form of the pap smear that was implemented, as mentioned earlier, in the 1950's. Despite the steadily dropping incidence of cervical cancer, there is still a virtual silence when it comes to discussing it. Because of its bodily site, and its relation to women's sexuality, there is perhaps some level of modesty involved. This view was mentioned by one of the participants. She recalled when one of her friends had cervical cancer and how she chose not to tell anyone for fear they would think she had led a promiscuous lifestyle. This is only anecdotal evidence, but perhaps it is indicative of a certain level of difficulty in launching public health awareness projects that women would respond to and feel comfortable with, without violating the boundaries of women's privacy.

While the number of breast cancer cases is much larger than that of cervical cancer, the relative rate of mortality in cervical cancer is actuallygreater than that of the breast. The total number of deaths related to breast cancer is higher, which makes it more familiar to the general public, but the percentage of deaths is higher for cervical cancer. Because cervical cancer involves aspects of women's anatomy that are viewed as highly private, bringing them into the fold in the same way that has been the case with breast cancer would be difficult. This understanding creates a catch-22; we can't talk about it because it is private, and it will always be private because we can't talk about it. This reinforces what the participant was saying about her friend's closeted cancer. Cancer is difficult enough to deal with when your family and friends are informed - what are the psychosocial consequences when one hides her cancer? Clearly an increased awareness of cervical cancer and its prevention wouldimprove the way this cancer is viewed.

This barrier, regarding a marginalized attitude towards the status of cervical cancers indicates the need for more consultation with women who have cancer in a formal way (on boards and policy committees) as well as informal discussion with staff members. These recommendations will be further discussed in the following chapter.

Women's Health

During the course of the research, many initiatives conceived by the cancer agency were mentioned. One strategy that was remarked on often during interviews was the cancer agency's agenda to decrease 'waiting times.' Almost all participants identified this as the biggest challenge in getting treatment. Most participants felt that wait times were of central importance because it is crucial to get treatment started so one can get on with one's life. A sole preoccupation with waiting times unfortunately implies that women with cancer have no other concerns in their lives. While a cancer diagnosis is a life altering experience for anyone, concerns with only 'wait times' is an over simplification of a very complex issue. An exclusive focus on wait times arguably conceals the need for psychosocial treatment and otherassistance. Concerns such as continuing employment, family care, sexuality, family planning, travel, and financial concerns might be as important or even more important for some women. Healthcare workers obviously deal with these concerns, but it is significant that wait times would be reported by healthcare workers as the most important issue for women with cervical cancer.

The 'Women's Health Strategy' which is a list of guidelines for reforming women's health, was adopted by Health Canada in 1999. This document was to assist at the national level to achieve the reform of women's health towards a 'women's health approach'. The first piece, 'Treating women the same way' indicates that at times

women's social/physical circumstances need to be acknowledged as different from men. Women are often the primary caregiver of children and the elderly in many households and their early discharge from hospital settings could be met with complacency, but can result in health complications from being over-burdened while at home. Thus, when health policy for women is developed it needs to take into account the roles that women have inside and outside of the home.

The second piece concerns problems that arise from 'treating women differently'. This applies to the problems discussed regarding women's experiences having cervical cancer. As in the aforementioned case where the friend was too scared to tell anyone that she had cervical cancer, there is a notion that because a women has the illness she has done something wrong. For instance although HPV is spread through sexual contact, the woman must carry the burden of cervical cancer because the disease does not manifest itself on men's bodies. Another example involves a potential vaccine for HPV. It has been suggested that a mass vaccination campaign would target women only - despite the fact that it is spread through male to female genital contact. These and other polices need to be examined for the ways in which women are 'treated differently'. Relegating women as different when it is not appropriate problematizes their bodies, and points to the need for more woman-centered policy.

The final issue concerns the fact that participants had no idea what a woman-centered policy was or what it would look like. Not only did they not know what it was, but they couldn't really understand why it was necessary. As I probed them regarding such things as childcare for women, family support, sexual health counseling, etc., they told a different story.

Childcare was something that almost all interviewees deemed imperative to this type of center. Women often come every day of the week for a short period of time (less than half an hour) for radiation treatments. For immigrants, new Canadians and marginalized persons, there are few options for childcare for such a short period of time. One of the participants suggested that they could bring their children to the cancer center, leave them in the waiting room and the receptionist could watch them, although this didn't seem like a reasonable solution to the problem.

Sexual health counseling was another hot topic. Many participants, once probed, mentioned that sexual education was a major need for the clinic. There was no one professional position in charge of addressing sexual health education, so when patients would work up the nerve to ask questions they were often told that they didn't know and didn't know who to ask. The two radiation therapists told me that it was the psychosocial oncologist's area, and the psychosocial oncologist told me it was a nursing issue. Nursing was unaware of whose area it was, but it wasn't (to the best of their knowledge) a nursing issue. Sexual health was therefore an area crying out for attention and as part of a comprehensive women's health policy this would be addressed directly.

The lack of knowledge of a women's health approach was a barrier that clearly affected the ability of the staff to meet women's health needs. However, while some staff indicated a lack of knowledge in certain areas, others were experts. Therefore, information sharing would greatly benefit provision of care in a women's health manner. We must also take into account that staff at this clinic are not experts in every area, and that perhaps there is a need for expert consultation.

Conclusion

The preceding discussion elaborated on the major themes arising from analysis of the data. The first goal was to provide first-hand insights via selected quotations from interviewees as they relate to the theoretical work explored in the literature review. Secondly, the discussion has laid out the barriers to care in hopes of guiding the reader towards the recommendations presented in the following chapter.

V Recommendations

This brief chapter outlines a sequence of proposed recommendations informed by the research findings in response to the barriers for the cancer treatment clinic where the study took place. Some concern issues identified by the participants and others are based on an analysis of policies from the clinic itself, as well as those originating from the federal level. All recommendations focus on improving the incorporation of a women's health approach to cervical cancer treatment and mitigating the effect of the barriers discussed in the previous chapter.

1. Evaluation

As previously mentioned, although several participants revealed that evaluations had taken place, they were unaware of the purpose and outcomes of the research. The rationale for evaluation surely is to ensure that patient needs are being met. Many participants felt strongly that patients were overwhelmingly satisfied with the treatment and services they received, but this needs to be proven through data collection and enhanced analysis.

Evaluation methods could include quantitative surveys for patients that focus on gender-specific treatment issues. Surveys targeted only at such issues as 'hours of operation' should be considered inadequate. Additional survey focus areas could include family/life issues, difficulties in health maintenance, sexuality concerns and psychosocial concerns. In order to ensure that appropriate issues are evaluated, collaboration among disciplines would be necessary. Psychosocial oncologists, who work directly with patients to overcome challenges, could take a central role in disseminating areas needing

evaluation. Evaluation will only be successful if it focuses on pertinent and real-life issues identified by the women themselves. Once initial quantitative surveys have been collected, findings should be summarized, disseminated to staff and other relevant personnel and potentially published in practitioner journals.

In order to target specific issues arising from the survey findings, focus groups should be conducted. Women currently receiving treatment or women who have completed treatment could be contacted to participate in focus group discussions on women's health needs. The findings of such evaluations add an experienced voice, which would raise awareness in staff on the implications of treatment and the individual experiences of patients. It could also prove cathartic for people who have undergone treatment. This opportunity encourages women to be active agents in changing or enhancing the treatment experience, the treatment environment and interactions with healthcare professionals.

2. Raising Awareness

From this research it is evident that the personnel who provide direct patient care to women with cancer have little awareness of women's health needs. Furthermore, there is limited, if any, gender-based analysis or evaluation taking place at the clinic. Though this is a case study of only one clinic, other research demonstrates that this is likely the rule and not the exception. For example, a report released by the Prairie Women's Health Centre of Excellence titled 'Invisible Women: Gender and Health Planning in Manitoba and Saskatchewan and Models for Progress' indicates that gender-based analysis and planning is absent in most regional and provincial health authorities. At the grassroots level, health administrators could begin to incorporate gender-based analysis beyond reproductive

concerns at the clinic. The report (Horne, Donner & Thurston, 1999) also made the following recommendation, which I believe is generally applicable to the clinic under discussion:

> We recommend that both the provincial governments and regional health bodies broaden their perspective on women's health beyond reproductive and family care-giving to encompass a broad determinants of health approach including gender as a separate determinant in practice as well as in their public relations materials. In addition, we recommend that eligibility for community-based health services not be based on the assumption that women are willing to provide unpaid care-giving services to family members.

Proposed in 1999, this recommendation is still pertinent nearly ten years later. While healthcare is a provincial jurisdiction, changes can be implemented first and foremost at the regional level. Arguably one strength of the clinic owes to a recent consolidation of services so that cancer care in the province is more centrally managed and distributed. While there will still be two centers in the province, services will be more collaboratively developed and implemented. With that, the implementation of gender-based analysis could be done province-wide through the centrality of the two cancer centers. In doing so, each center could pilot gender-based analysis in one specific treatment area, or introduce it throughout the whole clinic.

During implementation it will be important to incorporate evaluation as a way of measuring success or failure of the program. Following the guidelines laid out in recommendation one, women should be directly involved in the evaluation process. Healthcare practitioners working with women should be involved at all levels including reception and volunteering. If gender-based analysis is to be implemented it needs to be targeted at all persons involved in care.

3. Women of the Board

Two participants mentioned the presence of the lay advisory board. This board is comprised of selected professionals from the clinic, as well as 'lay-people' from the community who have experienced treatment or are family members of those who have had treatment. This is a wonderful step towards incorporating 'patients' into the development of patient care. To take this one step further, it might be suggested that the clinic lay-advisory board not be labeled as such, but rather become a clinic policy to incorporate women and men undergoing treatment to take part in the development of policies that affect their care. This will give survivors a chance to verbalize their opinions and it also erases the passive role of cancer patient/survivor. In keeping with inclusivity, I suggest not having a token 'lay-person' on the committee and especially not calling them lay-people. Labeling them as lay-people suggests they know nothing of which they speak. On the contrary, people who have undergone treatment and are asked (or ask) to join the board should be regarded as experts - perhaps not in the specifics of treatment protocols, but definitely in the area of patient care.

4. Expert Consultation

In order to facilitate gender-based analysis a position should be created to ensure successful and continuous application of gender-based principles. This person appointed would also serve as a liaison between patients and healthcare workers if gender-based concerns are identified.   This person could also work in cooperation with those conducting the evaluation to come up with solutions to gender-based barriers/issues. This person could be invited to meetings within all departments of the cancer clinic and act as an agent of change to promote more gender-based analysis at the clinic.

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The proposed position would include raising the profile of women's & men's health and gender-based analysis. This could include distributing literature to clients about the attempts at incorporating a women's health approach and also through public relations and literature posters around both clinics.

5. Staff Education

Many staff members identified their own knowledge gaps in a number of areas, which they were unsure of as women's health concerns. In my discussions with the participants, lack of knowledge about what a women's health approach involves was pervasive.

In general, the clinic needs to identify knowledge gaps and determine who will address these. Rather than continuing to be unsure about who is to do what, a pro-active approach should be adopted to address concerns affecting the care of the women with cervical cancer. Clearly there is passivity at the clinic regarding who would address sensitive issues such as sexual health. Though sensitive these issues need to be addressed. Without having to create and fill a new position these knowledge gaps need first to be identified. Next, program heads should take the lead. Staff committees should research best practices and present these to the staff to ensure unanimity and then education should be implemented into client care. It must be emphasized that the approach to treating sexuality and other sensitive issues like 'any other thing' is not incorrigible. When health-care workers devalue a person's feelings about something they feel is private it violates trust. This discussion concerns so-called embarrassing things such as sexuality, drug-use and sexual intimacy - but these can be conducted in a value-free and sensitive manner.

Furthermore, when healthcare workers identify knowledge gaps, these gaps should not be shrugged off due to cut-backs and politicking. If a knowledge gap is identified healthcare workers need to lobby to implement education and resources - not simply pass it off as owing to the powerlessness of politics.

6. *Promotion of Discussion*

Healthcare workers should be encouraged to dialogue regarding the shortcomings identified in the case study, but also to discuss concerns identified before this research took place. Providing a place to express concerns may well establish the recommendations already mentioned. A significant number of ideas arose from this research and came directly from those working in the clinic. Perhaps this research facilitated an outlet for the healthcare workers they had never had, or perhaps they never cared to share their ideas. Whatever the case, their ideas have the ability to transform this clinic into one they have imagined and even more.

The main component needed to facilitate discussion is time. Time needs to be set aside for healthcare workers to talk about issues significant to patient care. This is not to say that they all have to engage in daunting academic work, but just to dialogue regarding their concerns.

7. *Psychosocial Concerns.*

Arguably the single most important finding from this study concerns the fact that more research needs to be done with women who have cervical cancer to investigate the psychosocial implications of their cancer. Cervical cancer is less common than breast cancer, but it brings with it a unique set of challenges for women. Issues that seem to be

pertinent are: silence, stigma, sexuality and education. A lot of work is being done in the arena of cervical cancer, but much of it targets issues such as how to get more women into the screening programs, non-attendees and the physiology of the disease. Given its interconnectedness with HPV, the issue of social stigma affects many women. There are also a myriad of other psychosocial issues that accompany all women with cancer. This topic needs to be studied in depth.

Of similar interest would be research with women from rural and remote areas, as well as First-Nations, Aboriginal and Métis women. The participants often identified these groups of women having additional challenges regarding both screening and treatment, as well as being labeled more 'high-risk'. The question would be how these women feel about being described as 'high-risk', and how this affects their life and functioning. This question needs to be further pursued and perhaps the findings from such research would provide insight into screening and treatment solutions. By simply labeling people as high-risk nothing is solved – clearly there should be additional concern to answer the question of why they are higher risk.

Conclusion

While the recommendations suggested by the research are lengthy, they are actually quite limited in scope. There are probably many more recommendations that could be made but at this time it is important to focus on making manageable changes in a prioritized fashion. Arguably the most important place to start is to implement evaluations and to manage them in a responsible and active way. If rigorous evaluations are begun, it would be a most positive first step towards recognizing the needs of the women receiving treatment.

Concluding Comments

This thesis identifies a lack of women-centered content in health policy at a cancer treatment center in Urban Saskatchewan. Employing a modified case-study method and research techniques derived from IE, 9 healthcare workers across several medical disciplines were interviewed. Healthcare workers share their perceptions of the clinic policies, as well as their opinions and understanding of women centered policy and approaches. The ultimate aim of the research is to provide recommendations toward implementing a women's health approach.

The research was guided by a number of theoretical assumptions identified in the scholarly literature which form the basis for discussion throughout the document. These theoretical assumptions are largely derived from works critical of the authority of the biomedical paradigm, such as those of Sherwin (1998) on relational autonomy and how it applies to woman with cancer making healthcare decisions. She reminds us that autonomy is relational and situational, and less a fixed concept than healthcare providers would like to think. Michel Foucault's works (1973, 1979, 19 95) make clear the social implications of the spatial design and discourse characterizing the medical clinic. Situating the clinic in a critical theoretical light is not to devalue it but rather to provide a constructive, oppositional view which puts the people it serves at the forefront of concern. As Pauly-Morgan's (1998) thesis emphasizes, biomedical structures are rarely viewed critically, in part because they are cloaked in benevolence. Coming to this project with a critical perspective provides the reader with a frame of reference to question this benevolence.

Similarly, the limitations of this research are articulated early on in the document to inform the reader fully and statements concerning researcher reflexivity are included mostly to remove any notion of sterile objectivity. This assertion further solidifies the feminist perspective which informs this research project.

The 7 recommendations arising from this research bear similarities to those contained in a report released by the Prairie Women's Health Collective (1999). This report also assessed the presence, if any, of a women's health approach in healthcare facilities in Saskatchewan and Manitoba and similarly concluded with recommendations towards implementation. Additionally, the report made suggestions towards a multi-tiered approach to implementation. The multi-tiered approach was to aide implementation of recommendations by providing a framework to navigate the bureaucratic structures. Written in 1999, the report has been largely ignored by health structures at the provincial and regional level.

The current barriers to implementation of a women's health approach at the clinic were identified and discussed. In light of these, alternate methods of dissemination of findings from this research will be utilized. First, the findings are to be presented at a conference affiliated with the treatment center. Secondly, publication in scholarly journals targeting oncology professionals will raise awareness in an important segment of healthcare. This strategy will not only directly reach those who participated in this study, but also target other healthcare professional working in similar clinics.

The goals of this research project, as identified in appendix III, place an emphasis on raising awareness among healthcare professionals at the clinic. While previous work shows that this is a challenging task, choosing not to disseminate the findings widely does a disservice to the women receiving treatment. It is my hope that by targeting relevant

conferences and publication venues these research findings completed with the cooperation of this clinic will find their way into the minds of practitioners and ultimately the policies of Canadian clinics.

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Appendix I: Interview Questions

Current Information

1. Tell me about your job at this clinic:

• how long have you been here?

• what do you do?

• have you worked in an area of women's health before?

• what are the challenges to your job? The rewards?

• who are the "clients" that you work with?

Background Information

2. Could you tell me about your personal history (background, training, previous work experience)

that brought you to this job?

• previous jobs/education

• other interests, concerns, experiences that led to current position

Population Specific

In the time that you have been working here, what are the changes that you have seen in the conditions of your work and in the clientele that you work with?

4. What are the goals of the Saskatoon Cancer clinic, do you think? What are the goals of the clients?

5. When and how is the cervical cancer screening and treatment a successful or unsuccessful program?

• strengths/weaknesses

• who benefits, who doesn't?

• Do you feel that the program is designed for women with women in mind?

Policy Specific

1. Do you see yourself as being at all involved in any part of the policy process?

- What area: carrying out? Development? Change?
- How are the policies at the clinic developed?
- Are policies always adhered to?
- How are the policies specifically regarding treatment of cervical cancer developed?
- Are the policies developed in the clinic?
- Whatm if anything would you change regarding policy development at the clinic?

2. Do the health disciplines in the clinic work together?

3. Who is seen as the authority on policy development specific to treatment?

4. Are clients asked about their experiences with treatment?

- What is their opinion?
- How are women's specific needs catered to?
- Regarding treatment specifically, what would you change about the treatment process?

Appendix II: Letter of Informed Consent

<div align="center">

Cervical Cancer Treatment Policies in Urban Saskatchewan: A Feminist Case Study
Kristen Haase
MA Candidate, Department of Women's Studies
Saint Mary's University
Halifax, NS B3H 3C3

</div>

The thesis research concerns examining cervical cancer practice policies. I am seeking to uncover how policy is developed and whose interests are considered through the formation of treatment policy. The interview will deal with questions regarding clinic practices, roles, development of policies and women's health interests. I am hoping that you will agree to share your expertise as a policy maker and or practitioner for the purpose of this research.

The information collected will be used for my thesis in a Master of Arts in Women's studies at Saint Mary's/ Mount Saint Vincent Universities. The interview will take between one to one and a half hours, and with your permission, it will be tape recorded. You are free to refuse to answer any question that you deem irrelevant, and you have the right to withdraw from the study at any point by notifying me by phone or email. If so desired, a summary of the research findings will be made available to you.

All data gathered will be kept strictly confidential. All interview transcripts and notes will be kept in a locked box in my home or in a safe place at all times. To further protect individual identities, this signed consent form will be sealed in an envelope and stored separately from the audio-taped interview. Furthermore, the results of this study will be presented as a group and no individual participants will be identifiable.

This research project has been approved by the Research Ethics Board at Saint Mary's University, according to Tri-Council Ethics Guidelines. If you have any concerns about the ethics of this research project, please feel free to contact my research supervisor, Dr. Audrey MacNevin or the Chair of the University of Research Ethics Board at Saint Mary's University, Dr. John Young whose contact information is listed below.

Dr. Audrey MacNevin   Dr. John Young
audrey.macnevin@SMU.CA   ethics@smu.ca

By signing this consent form, you are indicating that you fully understand the above information and agree to participate in this study.

Participant Signature:_____ **Date:**_____

If you have any questions or concerns about the nature of this research, or the expectations, please feel free to call me at home or send me an email. Thank you very much for your participation in this research.

Kristen Haase (h) 306 843 2268, kristenhaase@hotmail.com

Appendix III: Research Goals

1. The main goal of the proposed research is to analyze the treatment policies regarding cervical cancer.

2. The second goal is to make policy recommendations towards a 'women's health' framework for treatment. A 'women's health' approach as described by Armstrong (1993) can be seen as a health approach which focuses on self-help, prevention, promotion and making informed decisions (p.130).

3. The third and final goal of the research is to initiate change at the clinic, whether through consciousness-raising in the interviews, or through attempts at drafting a re-conceptualized policy document. It is my hope that the proposed research will primarily and directly benefit the women who attend this clinic.

Research Ethics Board Certificate Notice

The Saint Mary's University Research Ethics Board has issued an REB certificate related to this thesis. The certificate number is: __06-087__

A copy of the certificate is on file at:

Saint Mary's University, Archives
Patrick Power Library
Halifax, NS
B3H 3C3

Email: archives@smu.ca
Phone: 902-420-5508
Fax: 902-420-5561

For more information on the issuing of REB certificates, you can contact the Research Ethics Board at 902-420-5728/ ethics@smu.ca .