This study is based on three focus groups I conducted in Gander, Newfoundland in 2003 for CBC’s show, ‘The Nature of Things’, that addressed whether hysterectomy is a necessary treatment option and what, if any, are the long term health effects of a hysterectomy. Using Feminist and Marxist paradigms I probe beyond what on the surface might be the women’s total enthusiasm for their hysterectomy procedure to explain a disjuncture between experience and reporting of experience. The voices of the Newfoundland women illustrate that both answers and questions may be more confusing and complex than they seem, and that outcome studies on women’s hysterectomy experiences or health, more generally, may underreport or misreport health concerns. Thus, this research challenges universal evidence-based outcomes of hysterectomy and calls for recognition of the multiplicity or diversity of standpoints women experience with hysterectomy.

Hysterectomy, the surgical removal of the uterus, is one of the most common elective surgical procedures performed on Canadian women between the ages of 35-50 (Cloutier-Steele, 2002). Hysterectomy rates in North America reached a high in the late 1970s (Hufnagel, 1989), and since the mid 1990s, the rates have been steadily declining, particularly in the 35 to 44 age group. That said, according to the Canadian Institute of Health Information’s (CIHI) website, more than 55,000 new hysterectomies are performed in Canada each year. Canadian women’s rate of hysterectomy — 22% — is high by international standards, double that of English and Swedish women, but somewhat lower than that of American women (CIHI; Farquhar & Steiner, 2002). Within Canada, rates vary significantly from province to province, with rates of hysterectomy in the Atlantic Provinces substantially greater than those in the rest of Canada. For example, a woman in Newfoundland has a 60% greater chance of having a hysterectomy than a woman living in British Columbia (CIHI). Rates not only vary among provinces, but there are also significant differences within them such as the fact that the 2002 rate
of hysterectomy in central Newfoundland is 22% higher than that of the St. John’s region (CIHI).

Medical research increasingly boasts of the benefits of hysterectomy based on quantifiable quality of life (QOL) research studies that found hysterectomy reduced or eradicated pain, eliminated health problems associated with heavy bleeding such as anemia, improved sexual relations (Davies & Doyle, 2002; Hartmann, 2004; Rannestad et al., 2001), as well as offered freedom from monthly periods and birth control (West, 1994). In contrast, Cutler (1998) points out that “bleeding and pain do not necessarily reflect disease” (p. 46) and, even when disease is indicated, treatment need not always be surgical. In matters of non-life threatening conditions, numerous research studies have shown that waiting does not compromise outcome, and, thus, should not be a determining factor in a woman’s decision whether to have a hysterectomy (Cutler, 1998). Whether hysterectomy indeed improves a woman’s quality of life is the subject of this research. Additionally, I argue that the quantitative measures of QOL do not accurately measure the true quality of life. Thus, in this paper I examine the ability of large surveys to accurately capture short and long-term health outcomes of hysterectomy.

This study is based on one of three focus groups I conducted in rural Newfoundland in 2003 for the Canadian Broadcasting Corporation’s (CBC) show, ‘The Nature of Things’. The groups were a central part of a show that aired in September 2005 addressing whether hysterectomy is a necessary treatment option and what, if any, are the long-term health effects of a hysterectomy.

To better understand the complexities of women’s experiences post-hysterectomy, I draw from Karl Marx’s theory of alienation (1967) and Feminist Standpoint Theory (Smith, 1987). Alienation for Marx, signified loss of control, particularly loss of control over labor, and thus loss of control over every aspect of an individual’s life. Extrapolating to women’s health in general, alienation identifies the role of social power and control in the relationship between a woman and her physician.

Dorothy Smith, in 1987, published *The Everyday World as Problematic*, in which she challenged conventional sociological thought for viewing the world from the vantage point of men. The starting point of social inquiry, according to the standpoint theory, is through an exploration of the dailiness of women’s lives in relation to their social, political, economic and historical contexts. Smith particularly finds Marx and Engel’s originally formulated problematic relevant in providing comprehensive insight into the activities of a woman’s life (Marx & Engles in Smith, 1987, p. 99-100):
Individuals always started, and always start from themselves. Their relations are the relations of their real life. How does it happen that their relations assume an independent existence over against them? And that the forces of their own life overpower them?

Smith believes that in order to deconstruct the gender relations of power, the starting point must be the everyday life as the problematic. Thus, using Feminist and Marxist paradigms I show that research that begins with women’s experiences may challenge the validity of larger surveys. In this article I capture a transformation process in relation to individual and collective interpretations of hysterectomy experiences. I probe beyond what on the surface appeared to be a group of Newfoundland women’s enthusiasm for their hysterectomy procedure to explain a disjuncture between their lived experiences and their reporting of these experiences.

The Historical Context

Cloutier-Steele (2002), in her book Misinformed Consent, believes there is “little rhyme or reason in how doctors prescribe … this often life-altering operation” (p. 9). Her experiences challenge research that shows hysterectomy improves a woman’s quality of life, so why are hysterectomies so prevalent? The answer to this question is not straightforward and may be rooted in women’s collective history with medicine. Thus, I first provide a historical overview in order to understand the social forces that shape medicine’s view of women’s bodies.

In 1973, Ehrenreich and English produced a pamphlet entitled “Complaints and Disorders: The Sexual Politics of Sickness” arguing that, “Medical science has been one of the most powerful sources of sexist ideology in our culture” (p. 5) by defining “women as sick, and as potentially sickening to men” (p. 5, emphasis in original). The view that all female ailments are attributed to problems of the reproductive organs is deeply embedded in the history of western medicine. For example, Hippocrates, answering the question, ‘What is woman?’, answered “disease” (in West 1994, p.18). Mitchinson (1998), who researched women and their doctors in Victorian Canada, argues that, “culture influences physicians to see women in a particular way and physicians provide the culture with the scientific legitimacy for doing so” (p. 142).

The history of gynecological surgery begins in the 19th century, a time when the uterus was believed to be the source of every possible complaint a woman could have. The decision to have a hysterectomy was not made by the woman, but rather by her father, husband or doctor to treat overeating, painful menstruation, masturbation, sexual arousal,
or promiscuity. Throughout the twentieth century, medicine continued to reinforce and justify medicalization of women’s reproductive health. The predominant view was that a woman’s uterus is troublesome, a disease-bearing organ ultimately disposable after childbearing years, as this American gynecologist in the 1960s claimed: “The uterus has but one function: reproduction. After the last planned pregnancy, the uterus becomes a useless, bleeding, symptom producing, potentially cancer-bearing organ and therefore should be removed” (Wright 1969, p. 561). Such views continue to prevail (Schofield et al., 1991, p. 1135).

Evidently, many present-day myths and misinformation about a woman’s body are centuries old. The erroneous belief that the uterus is important to the woman’s body only for purposes of bearing children contributes to the continued high rate of hysterectomy (Schofield et al., 1991; Vilos, 1999). Women over the age of 40 who have completed their families and who experience gynecological problems are more likely to be offered the “just in case [this is cancer]” scare tactic to convince them that this is their best option (Cloutier-Steele, 2002, p. 10). However, the importance of a uterus in a woman’s life goes beyond its role in childbirth as it is deeply connected with sexuality, sex, health and general well being (West, 1994).

The women’s health movement since the 1970s has been critical of “excessive medicalization” of women’s bodies (Lock 1998). The continued reinforcement of negative stereotypes, according to feminist scholars, is a means by which economic and political reification maintain patriarchal power and control over women (Martin, 1992; McCrea, 1983; MacPherson, 1993). However, Morgan (1998, p.86) points out that western medicalization is “extraordinarily” more complex than relations of power and social control, and contemporary medicalization has been contested and resisted. Contestation for Morgan “involves the (re)claiming of women’s subjectivity, women’s agency ... [and] the (re)claiming of epistemic power” (109). Resistance is illustrated by challenging medical knowledge through sharing experience, theorizing experience as knowledge, pursuing non-medical literature and challenging medical research and technology. Consequently, women do not solely depend on physicians’ opinions and recommendations; rather they tend to rely on outside sources for information (Kaufert, 1980; Voda,1993; Gullette, 1997), and the notion of woman as an ideal or complacent patient is outdated (Morgan, 1998). The lack of confidence in medical knowledge, the preferred choice of lay information is indicative of women’s resistance of medicalization. Lorentzen (2008) also describes two ways resistance can challenge patient-physician power relations, either direct through confrontation or indirect by ending the doctor/patient relationship.
Brubaker’s (2007) interviews of 51 poor African American teen mothers on their experiences with reproductive health care (p. 528) also demonstrates that the discourse on medicalization needs to be expanded to include agency (through resistance). She found that “the teens’ descriptions of their experiences with prenatal care and birth suggest that they strategically embrace and reject various aspects of medicalization” (p.546).

Variations in Hysterectomy Rate

With the exception of cancer and hemorrhaging, there is no consensus within the medical profession as to when a hysterectomy is indicated. The mere fact, according to West (1994, p. 17), that “one-third of all the women in the United States will develop problems severe enough to warrant hysterectomy just doesn’t make sense”, and implies that many hysterectomies are medically unnecessary. Explanations for variations in hysterectomy rates in North America include individual practice styles of physicians (West, 1994), poor understanding of surgical morbidity (Carlson et al., 1993), and lack of universal availability of modern equipment which can provide alternative surgical treatments (Naylor et al., 1994; Vilos, 1999). Medical researchers committed to understanding rate variations believe the best method to reduce and equalize hysterectomy rate is through more effective treatment practices (Wilcox et al., 1994).

Although treatment practice explains a large variation in the rate of surgery, there are other non-medical factors such as income, education, religion, culture, and personal preference that may influence hysterectomy rates. Research since the 1990s from New Zealand, Australia, Britain, US and Canada has consistently found an inverse relationship between rates of hysterectomy and socioeconomic status (Brett et al., 1997; Cooper et al., 2009; Dharmalingam et al., 2000; Kjerulff et al., 1993; Spilsbury et al., 2006; Vessey et al., 1992). Black women with lower income and education have twice as many hysterectomies as white women (Meilahn et al., 1989). Overall, however, rates of hysterectomy are highest for black women compared to other racialized groups (Keshavarz et al., 2002). Lower rates of hysterectomy have been associated with increased levels of education (Basinski, 2002; Cooper et al., 2009; Meilahn et al.,1989). Recent research from Britain and Australia, found that the inverse relationship between hysterectomy and education is particularly strong in middle-aged women and weak or non-existent for women born in the 1920s and 1930s (Cooper et al., 2009).

Adverse Effects

Like any major surgery, hysterectomy involves complications, risks, and short and long-term effects. Complications and risks include
blood transfusions, which are common during hysterectomies and put patients at risk for AIDS, CMV and hepatitis, blood clots and hematomas, thromboembolism, urinary tract problems, infections and lung and bowel complications (Cloutier-Steele, 2002; Vilos, 1999, Hufnagel, 1989). Some of the after-effects associated with hysterectomy include: postoperative depression, earlier menopause, increased risk for cardiovascular disease, changes in libido and sexual pleasure and increased bladder problems (Cloutier-Steele, 2002; Vilos, 1999).

Despite these potentially serious health-effects, the medical literature is replete with articles boasting the benefits of hysterectomy citing high level of patient satisfaction (Carlson et al., 1994; Davies & Doyle, 2002; Hartmann, 2004; Naughton et al., 1997; Rannestad et al., 2001; Vilos, 1999). However, the findings of these studies dramatically stand in contrast to Cloutier-Steele’s (2002) experiences, and the 13 women who contributed to her book. The introduction to the shared stories captures the women’s experiences in a more general way (p. 28):

We are alive but in different selves. Many of us feel like outcasts from our previous lives. Too many of us grieve for loss of spirit, vitality, identity, the birthright of innate femininity, and the pure joys of sexual awareness.

Similar stories of adverse effects are shared by women in an ongoing online study (since 1991) conducted by Hysterectomy Educational Resource Services (HERS). More than 75% of the women (n=1000) who had a hysterectomy reported irritability, personality change, loss of energy, profound fatigue, diminished or no libido, more than 60% said they had loss of stamina, had experienced insomnia and bone and joint pain, and over half the women stated weight gain, nervousness and anxiety as after-effects to their hysterectomy (Coffey & Schweikert, 2009).

Other research based on qualitative studies has found mixed results. Elson (2002; 2004), for example, found that differing narratives capture positive (no more pain and heavy bleeding), negative (loss of menstruation and a sense of connecting to other menstruating women) and ambivalent experiences (2002, p. 46). Elson (2002) concludes that, “Universal advice on the adverse outcomes of hysterectomy is not evidence-based and medical texts should be updated to reflect the diverse experiences”. Markovic and colleagues’ (2008) research in Australia paralleled those of Elson (2004), also highlighting differing experiences influenced by socio-demographic backgrounds, previous health history, the quality of doctor-patient relationships and contemporary views about gender roles and identity (pp. 464-475).
Given this, how do we explain the differing reports on women’s experiences of hysterectomy? Davis (1986), an anthropologist who critically examined the “utility and validity” of quantitative and qualitative research in understanding “The meaning of menopause in a Newfoundland fishing village” (p. 73) questioned the reliability and validity of her quantitative data as she believed the women in her study “had problems ranking response data, found questions to lack sufficient context, and were personally offended by directed questions involving self-assessment (p. 90). For example, she found that in questions related to self-esteem, women “check the most modest answer despite the fact that they take great pride in their appearance” (p. 90).

There are growing concerns expressed about the validity of research that measures patient satisfaction (Avis et al., 1997; Schofield et al., 1991; Teijlingen et al., 2003). For example, Schofield et al. (1991) found a disjuncture between self-reporting morbidity (59% of women reported the hysterectomy caused or worsened at least one symptom) and overall satisfaction (97%). The researchers offered three possible explanations: first, the benefits of the surgery outweighed the problems; second, there is resistance among patients to express dissatisfaction with their medical care; and third, perhaps women prefer to “focus on the more positive aspects and to minimize any problems experienced” (Schofield et al., 1991, p. 1135).

According to Avis et al. (1997), patients commonly report high levels of satisfaction, due to “social desirability bias, reluctance to express a negative opinion, and the wording of questions” (Avis et al., 1997, p. 85). Bernhard (1986, p. 120) believes that “sensitive topics such as hysterectomy may garner “socially responsible answers rather than [a woman’s] own answer”. A review of patient satisfaction surveys by Sitzia and Wood (1997) concluded that patients “ingratiate themselves with researchers or medical staff”, particularly if there is no anonymity; and negative comments may adversely affect future treatment (Sitzia & Wood, 1997, p.1836). Teijlingen and colleagues’ (2003, p. 79) research on ‘maternity satisfaction studies’ similarly argue that respondents tend to answer positively as they do not want to appear critical of their caregivers. Furthermore, they point out the “people’s experiences and preferences are shaped by what they ‘know’ ” (2003, p. 80). Finally, Sitzia and Wood (1997), forewarn that researchers should be careful in their interpretation of a positive survey response. Such a response may simply mean “that nothing ‘extremely bad’ occurred” and that “dissatisfaction is only expressed when an extreme negative event occurs” (p.1840). Women, particularly, according to Schofield et al. (1991), interpret difficult health situations positively.
METHODS

To capture the experiences of women with hysterectomy I carried out three focus groups in Gander, Newfoundland: two with women who did not have a hysterectomy and one with hysterectomy. However, the narratives of the women who did not have a hysterectomy will not be included in this paper, as they do not address the direct effect of experiences with hysterectomy. Focus group interviews are an effective method to capture women’s individual experiences with hysterectomy and, as Morgan would state, “to make collective sense of them” through their interactions within the group setting (2004, p. 277). Wilkinson explains, within the context of a group, a process of “negotiating and renegotiating” meaning continuously occurs (p. 277). Newfoundland was the preferred province to hold focus groups because throughout the 1990s, Newfoundland had the highest rate of hysterectomy in Canada. The demographics of Newfoundland are also interesting as poverty rates are high, and education levels are low compared to other provinces in Canada (Census 2001).

A student researcher helped assemble the participants of the focus groups. The sample was solely selected through word of mouth or snowballing, and 3 focus groups were organized: two groups with seven women who never had a hysterectomy; and one group with women who had hysterectomy—there were 9 women in this group. The participants in the focus group were diverse in terms of education and occupation; many, however, did not have education beyond high school and they worked mostly in pink-collar jobs. At the time of the hysterectomy, the average age of the women participants was 32.7 (three were in their 20s, five in their 30s and the eldest was 41), substantially younger than the national average (the age range for hysterectomy in Canada is between 35 and 50, the average age being 42). With the exception of one woman, all were married with children.

The women were not prescreened and anyone who wanted to participate was able to do so. Initially, many were very nervous about not only talking in a focus group but also about being televised. Thus, the make-up of this group included both women who were shy and those more confident in public situations. However, all the women were active participants and there were no indications that the filming of the focus group had either a silencing or a grandstanding effect. Consent for interviewing, video recording and broadcasting were given. Ethics approval was given in accordance with CBC’s guidelines. This focus group lasted over three hours. I used an inductive approach to analyze the data drawing on the grounded theory method (Strauss & Corbin, 1990). The videotapes were transcribed by CBC, and I coded the
transcripts by themes identified both in the literature and from the participants’ narratives.

**The Focus Group Findings**

At the start of the focus group, the women were asked three questions: 1) why were you offered a hysterectomy; 2) how you felt at the time you were told you needed a hysterectomy; and 3) how do you feel about the hysterectomy now? In response to the first question, numerous reasons why a hysterectomy was offered to these women included abnormal pap smears, general discomfort, pain, back problems and swelling of legs and arms, heavy menstrual bleeding, and endometriosis. Aside from a D&C, a procedure which is commonly recommended but neither cures nor manages symptoms, no alternative therapies were recommended:

*I actually found an article in the newspaper about a procedure that they were experimenting with at a university in Toronto and it had to do with burning the lining . . . Anyway brought it down to our gynecologist well he went nuts . . . So we didn't really have a good discussion about the possibilities of that procedure.*

*I had my hysterectomy when I was 30...I started having heavy periods. And my blood count was going down. I was offered D&Cs which I had 2 or 3 D&Cs, and they didn't work. So my gynecologist offered me hysterectomy. Which I gladly took and don’t regret it.*

The recommendation of a hysterectomy came to no one’s surprise. These women confronted the challenges of accessing healthcare in rural areas: they were unable to pursue a second opinion or alternative therapy locally:

*There wasn't a whole lot of options. If there was more and I think because we're living on an island and I mean we do get a lot of doctors that are from other countries coming to Newfoundland, I think that we may not be given options that other hospitals are given to their patients. ... could be one of the reasons why there are a lot of hysterectomies in Newfoundland. ... so you know lot of factors to what options are given. Gonna depend on what the*  

---

1 Quotes separated by paragraphs denote the voice of a different group member. Two paragraphs represent two group members, three paragraphs three group members, etc.
doctor how the doctor feels and what they feel they want to do really.

The decision to have a hysterectomy largely depends on physician practice style, which in Newfoundland is rooted in a long cultural history of hysterectomy.

My mother had a hysterectomy when she was 34. And my grandmother had a hysterectomy when she was 36. My mother has six sisters and five have had the hysterectomies. And beyond that, there’s probably more.

As such, hysterectomy for many of these women was viewed as a normative event, a natural occurrence in a Newfoundland woman’s life course. To support their hysterectomy decisions, gynecologists drew on this knowledge and urged their patients to discuss their concerns with other women who had the surgery.

Actually my gynecologist told me that the best thing for me to do was talk to people who’ve had it done. And who’ve had it done several years before. And I spoke to my mother and I asked a few friends at work who I knew had it done.

With one exception, the women were initially wholeheartedly enthusiastic about their hysterectomy experience. And this enthusiasm was repeated and repeated in statements such as the following from four different women:

Oh yes. Big difference. No problems since actually.

I’ve never . . . regretted it; I own three pairs of white pants.

. . . if I had to, I’d do it all over again because I feel great. It was a job well done.

I was happy to have it done.

I’m glad I had it. I do have my life back. You’re right. That’s how I feel and I can wear white pants too.

The women’s positive experiences with hysterectomy were consistent with the literature reporting high levels of patient satisfaction (Davies & Doyle, 2002; Hartmann, 2004; Rannestad et al., 2001). I admittedly found the unremittingly enthusiastic responses to the
benefits of hysterectomy somewhat puzzling in light of what was said and the qualitative literature that focuses on women’s individual experiences (Cloutier-Steele, 2002). My puzzlement aside, I reoriented the discussion to the immediate post surgical experience because, according to the literature, compared to other abdominal surgeries, the recovery period from hysterectomy is longer and more difficult (West, 1994). I was curious about how the women experienced and understood this aspect of the procedure and its possible relation to post-op satisfaction. Interestingly, the tenor in the room at once shifted from enthusiasm to exasperation. For most of the women, recovery was long and difficult - a stark contrast to the 6 to 8-week time frame their gynecologist predicted:

It was just an amazingly difficult surgery to recover from.

I tell you that the shocking thing was the first time that I got out of the house, I could hardly recognize my neighborhood; it was like (laugh) everybody painted their house. But I missed it all ... It took me about 15 weeks before I felt like I had enough strength to go back to work.

But, 15 weeks turned out to be a speedy recovery; one year was more typical:

I remember I had my surgery in the spring of the year, and that spring, one year later, I was able to get out and walk and feel like I had oomph and energy and enthusiasm for life again, because I really . . . It just took the life out of me, it really did . . .

Many of the women shared stories of ubiquitous crying. Some women cried because they were grieving the loss of their uterus:

I know a few women who are younger who had hysterectomies in their 20s and even though they’ve had their children and didn’t want anymore children, they’re still, you know, it’s a part of their femininity.

For some, crying was a response to sadness, “emptiness” and a lack or curtailment of future childbearing choices:

I was 27 when I had my first child . . . 29 had my second. But . . . people are having kids ‘til they’re in their forties . . . I would have liked to have had a third one . . I’m still not too old to have a child
...maybe if I had had another choice, I could have had another child.

Others saw their crying as a post-operative after-effect; mood swings, they believed were an outcome of the surgery:

And I was always outgoing, never discouraged, I was always optimistic and since [the hysterectomy], I mean I second-guess myself more now than I ever did.

Many of the women reported stories of long-term physical and emotional health effects, directly attributed to the hysterectomy:

I've always had fluid problems since [the hysterectomy]. My feet are swelling all the time. If I wear socks you can see the imprint after a couple of hours, that type of thing, or any kind of emotional problems, which I have highs and lows. I've never had them before.

I was going through a lot of the menopausal-type things you know because of the post-menopausal and I would experience the hot flashes and the night sweats and all those kinds of things. So it's really since... the patch that I feel myself which is like five years later.

Symptoms and concerns were raised with their doctors and were at best “brushed off to one side as being nothing really” or, more typically, patronized as captured by this one woman’s experience:

[My doctor] was a general practitioner and when I spoke to him about [sex] and it was a big concern to me because I mean I was in my mid-20s and having these problems and I’m thinking: God, what is wrong with me? ...[T]here was nothing that I could do to prevent pain. And he basically told me that I was probably allergic to sex...

The women’s experiences demonstrate the prevalence of misogynistic health practices today. Reducing all symptoms to psychosomatic illnesses is a means of reinforcing historical myths about women’s biology that women are sick (Ehrenreich & English, 1973; 1978; Hubbard, 1983). Even though the Newfoundland women did not feel their health problems were psychologically rooted, the impression they were all too often left with was that, “it was all in your head”:
And then emotional problems which my doctor told me that was probably panic attacks, a bit depression and that type of thing and I knew I wasn’t. If it was, I would have agreed. He sent me to an internist who in turn had a consult for me to see a psychiatrist. I told him to use it on himself because I didn’t want it.

This woman admitted to the group that although she experienced emotional turmoil, she nevertheless resisted a diagnosis that was psychologically rooted. And, she was right, as her ‘emotional’ problems turned out to be a thyroid problem.

From a medical perspective, the hysterectomy for these women was successful; the bleeding stopped, the abdominal pain disappeared. Yet, many of the women felt that “there’s [something] terribly wrong”. A new set of physical and emotional problems emerged months after the hysterectomy which they never had before—women reported experiencing early menopause, blood clots, thyroid problems, weight gain, fluid retention, and disrupted sleep. The reaction to or understanding of these symptoms varied. Whereas some women had an overriding feeling there is nothing more to be done: “I just had to go through whatever I was going through”, other women pursued medical consultation with their family practitioner. Their ‘new problems’ were viewed as non-gynecological and referrals were made to other specialists:

. . . You know you go to the internist, does the gynecologist know that? No. If you’re having mood swings, panic attacks, you’re sent to a psychiatrist. Again, the gynecologists don’t know this. So like where does the fault lie?

The gynecologist typically schedules a six to eight week post-surgery follow-up appointment, the indicated recovery period for hysterectomy. The patient is then “discharged” to her family practitioner and unless a new gynecological problem arises, it is unlikely that she would see her gynecologist again. The challenge that emerges from these stories is establishing links that are not readily apparent between new and old health conditions.

**DISCUSSION & CONCLUSION**

There is the story of a veterinarian who informs the family that the surgery of their pet was a success but the pet died. There is cautious laughter at the telling of this story. The story in itself is not funny but the humor is meant to mock the doctor’s bedside manner and to deride the medical interpretation of success. The stories of the Newfoundland
women who had hysterectomies in many ways reflect the above aphorism. At face value, these women’s experiences would support the medical literature that reports health improvement after hysterectomy. But, through further probing, accounts of new health problems surfaced, probably due to the iatrogenic effects of surgery.

This research raises many interesting issues such as the compartmentalizing of health experience, doctor-patient relationships, and the validity of large surveys to accurately report women’s health experiences. It is curious why the Newfoundland women boasted good-health when in fact they experienced numerous health problems. This contradiction is similar to that observed in Schofield et als.’ (1991) study where there was a disjuncture between number of symptoms women reported and their overall satisfaction with the hysterectomy. I can only speculate why this occurred. Perhaps enthusiastic comments such as, “I’ve never regretted it, I own three pairs of white pants”, early in the group interview produced a “group effect” where group members are easily influenced by one another. Although the “group effect” phenomenon is a common critique of focus groups, Morgan (2004), instead, argues that “the group effect” in fact enhances the research process as “the participants both query each other and explain themselves to each other” (2004, p.272). Furthermore focus groups are able to delve “into the sources of complex behaviors and motivations” (2004, p.272). Thus, a comment by one of the women appears to capture the decision as well as the complex forces/factors affecting that decision:

\[ \text{I think though today though, if... If I still had my uterus... I don’t regret having a hysterectomy. I mean the way I was going back then there were no other options other [than] a D&C which I had tried. But today they have so many other things, they have the TCRE, and the... I mean every... it seems like every year they’re coming up with something new, that at least you got something else to try before you go to that final point.} \]

On the surface what may appear as a contradiction, is perhaps an attempt to make sense of or justify past decisions. After all, there was no recourse as, “I’ve already had the surgery... I just had to go through whatever I was going through.” Similarly, Teijlingen and colleagues (2003, p.76) found that higher satisfaction reporting among women may occur when there are few available choices, which in turn lead to low expectations.

Marx’s (1967) theory of alienation provides a framework to understand the contradictory responses between experience and reporting of experiences described above. According to Marx, the unequal relations between the workers and the owners of production...
create exploitative conditions where the worker is removed from any decision-making processes related to production. Loss of control over their labor means loss of power and control of their individuals’ lives. Extrapolating to women, and women’s health in general, alienation is rooted in women’s collective health history, where medical practice holds power and control over women’s bodies (see Ehrenreich & English, 1973; MacPherson, 1993; McCrea, 1983), and to hysterectomy in Newfoundland specifically, this means standard medical practice leads to the women’s loss of control over their natural relations, means of reproduction, relations to others and ultimately to themselves. Thus, alienation results in a schism that is created between what one views as ideal and the reality of the everyday experience. To overcome the schism, acts of resistance are necessary to take ownership and control over one’s life (Brubaker, 2007; Lorentzen, 2008). Acts of resistance for the women in Newfoundland is interpreted through a model of agency (Morgan, 1998; Lorentzen, 2008).

Women’s health culture in Newfoundland normalized hysterectomy, and hysterectomy was what these women “knew” and came to expect. As Marx would say “…since they are accustomed to move about in such relations, they find nothing strange therein” (1967, p 779). For the women in Newfoundland, alienation was experienced by patronizing doctor-patient relations where symptoms were often dismissed. Once the hysterectomy was complete, then there were no other options but to “make do” or according to Marx, a need for “reconciliation…of these relations in their everyday life” (1967, p. 779). “Making do”, according to Aptheker (1989), is a daily process, which “allows to take the patterns women create and the meanings women invent and learn from them (1989, p. 39)”, and requires intuitiveness, strength, creativity, resourcefulness and “a belief in life” (p. 73). Making do for the Newfoundland women is when “there was no alternative [to the hysterectomy] offered. I did what the doctor suggested”, and now “I have no regrets”.

Making do can also function as a collective form of agency through resistance. Women’s reluctance to report health problems may be an outcome of a personal history of frustrating doctor-patient relationship where the “woman’s normal state was to be sick” (Ehrenreich and English 1978, p.100 - emphasis in original). Perhaps then, the “normalization” of side effects is a form of passive resistance (Lorentzen, 2008) to the hegemonic medical beliefs that historically have constructed women’s natural state as weak and unhealthy. This may particularly be the case for women who do not have the means nor the resources (education) to challenge “gendered medical knowledge” (Lorentzen, 2008, p. 71), and who have little decision making power in their individual lives. The Newfoundland women repeatedly shared stories of
symptoms all too often rebuffed and replaced with a mis-diagnosis of “it was all in your head”. Such diagnoses were resisted: “well, I think anybody taken off the street could have hidden emotional problems and I really didn’t think I needed that”, even though in this instance the woman experienced severe mood swings. The dilemma for these women was either to admit their surgery was not all that it was meant to be or to report their surgery to be a success: “I’m glad I had it . . . I can wear white pants too”. The former signifies loss of control; the latter “I do have my life back”.

CONCLUSION

This study shows how hegemonic views of women and their health shape the delivery of services and in turn how women are both active and passive in determining their health experiences (Brubaker, 2007). Each woman’s experience is situated in an intricate narrative that begins with the reason hysterectomy was offered, the experience of hysterectomy and the direct and indirect effects of hysterectomy, underpinned by patriarchal practice styles and socialization processes that view hysterectomy as a normal occurrence in a woman’s life course.

The stories of rural Newfoundland women revealed how outcome studies on women’s hysterectomy experiences or health, more generally, may underreport or misreport health concerns. If health indeed is underreported, the full effect of hysterectomy on women’s health goes unrecognized and those most vulnerable – poor, less educated women - continue to be at risk for procedures, which can adversely affect their long-term health. Socially and/or economically disadvantaged persons generally do not seek information to assist with health decision making, as they confront such barriers as cost, living in a rural environment, literacy, health limitations and limited or no ability to use information technology (Eng et al.,1998, p. 1371). Instead, they rely on their physicians to provide accurate and reliable information, hence, the importance of research that accurately measures post-operative short and long-term experiences. Thus, the importance of this study is that it forces us to think not only about how questions are asked but also how they are answered, and that researchers should be mindful that questions must probe beyond the obvious, making links where links are not readily apparent.

This study builds on a growing literature (Elson, 2002, 2004; Markovic et al., 2007) that challenges universal evidence-based outcomes of hysterectomy and calls for recognition of the multiplicity or diversity of standpoints women experience with hysterectomy. My research particularly brings to the forefront the importance of challenging the validity of larger QOL surveys in capturing, as Smith (1987) would say,
'one true story', which is nothing more than a partial perspective claiming generality on the basis of social privilege and power ” (p. 121). To generate health policies that address in a meaningful fashion women’s health experiences and needs, research therefore must begin from the standpoint of women health experiences and needs. Otherwise, policies generated from incomplete research will continue to reinforce health service delivery that reproduces health inequalities.

REFERENCES


(CIHI) Canadian Institute for Health Information.


Hysterectomy Educational Resources and Services (HERS). Adverse effects data. [http://www.hersfoundation.org/effects.html](http://www.hersfoundation.org/effects.html)


model for mixed methods, *Qualitative Health Research* 18 (2): 280-293.


