SIMPSON BREAST CANCER AND THE DISCOURSE OF RISK M.A.

BREAST CANCER AND THE DISCOURSE OF RISK

By

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ABSTRACT

This thesis explores the role of values in risk assessment for breast cancer. Why? First, breast cancer poses a serious health threat to women, yet currently has no known cause. This means the discussion of risk becomes central to this disease. Second, K.S. Shrader-Frechette has shown that values enter in at each stage of risk assessment. These stages are the choice of topics, methods, and evaluation. By using Shrader-Frechette's framework for analysis of such areas of breast cancer as mammography, prophylactic mastectomy, tamoxifen and the role of estrogen, research routes, and prevention, it can be shown that certain values dominate the risk assessment. These values are the technological imperative, individual causation of disease, and reductionism. This thesis argues that the dominance of these values has led to a narrow and biased view of breast cancer risk. This view leaves women with fewer legitimate choices for the management of breast cancer risk and in many ways excluded altogether from its risk discourse. As breast cancer advocacy groups have gained in strength, attention has been drawn to the fact that there are competing values which can be used in risk assessment for this disease. These competing values are a low-tech/high-preventative, holistic, care-oriented approach to disease. These values can provide a viable alternative assessment of risk in breast cancer. Furthermore, this alternative risk picture is more desirable than the current one, because it helps to redirect and widen the focus on risk in breast cancer and gives women a central role in its risk discourse.

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INTRODUCTION

Breast cancer is a common topic of discussion today, but is one which is surrounded by much controversy. Women's advocacy groups are demanding more funding for breast cancer research and want to have a say in which areas of research this money should be directed. The media report on the latest development in the fight against breast cancer while emphasizing its risk factors and survival statistics. Feminists are using breast cancer as an example of the oppression of women within medicine, by questioning the extreme forms of manipulation which are being recommended for the management of breast cancer risk. These issues, among others, are part of this controversy.

Breast cancer does pose a serious health threat to women in today's society. What poses an even greater threat to women though is the biased risk discourse and assessment surrounding breast cancer, including its prevention, diagnosis, treatment, and research. This biased risk discourse has skewed the focus on breast cancer in such a way that women are left with fewer legitimate choices for the management of breast cancer risk and are in many ways excluded altogether from the risk discourse. For example, most research into the causes of breast cancer focuses on the woman's body and what has "gone wrong" with her physically to cause this cancer. This determines risk factors for breast cancer which are only related to a woman's biological functioning and development (see Appendix A). The effect of the environment on a

woman and its possible role in the development of breast cancer is rarely studied. I want to claim that it is a narrow or restricted definition of risk which has, in part, led to this present focus of breast cancer research.

Given the value-ladenness of risk assessment, I will argue that certain values predominate in the current breast cancer risk discourse and are responsible for this narrow and biased focus. These values override other competing values which can, as I will show, provide a viable alternative assessment of risk in breast cancer. I will further argue that this alternative assessment is more desirable because it helps to redirect and widen the focus on risk in breast cancer and it gives women a central role in the ensuing risk discourse.

This thesis will be argued for in the following manner: First, I will show that values are operating at the different levels of risk assessment in breast cancer. K.S. Shrader-Frechette's analysis of the role of values in risk discourse will form the framework for this examination. Such examples as mammography, prophylactic mastectomy, tamoxifen and the role of estrogen, research routes, and prevention will be discussed. Second, I will demonstrate how the values which dominate these discussions lead to a narrow risk focus that in turn results in certain outcomes which can be questioned. The third part of this argument will challenge these dominant values and offer the above-mentioned alternative view of breast cancer based on a different value-structure.

The first chapter will briefly explain Shrader-Frechette's analysis of risk

assessment and values. The five areas of breast cancer risk management which I want to examine form the second chapter. A discussion of the role of medicine in society and the feminist perspective on this role is offered in the third chapter forming the basis for the conclusions of this thesis. These conclusions, including a more complete indication of what the alternative view of breast cancer involves, are also found in chapter three. Two appendices, one on the risk factors for breast cancer and a second on definitions of risk, have been included as a means of providing a more complete background for this thesis.

CHAPTER ONE: RISK ASSESSMENT

Much of the recent research and thought on risk assessment has tried to unravel the different factors which come into play when a decision on risk needs to be made. One of the biggest shifts in thinking about risk has been the discovery and identification of the role of values in risk discourse[1]. No longer does the determination of risk via statistical methods enjoy its objective authority in discussions. As we are now beginning to realize, value judgements are an integral part of risk; a part which needs to be explored and made explicit if we are to more fully comprehend how "risk" is calculated, communicated, perceived, and accepted.

K.S. Shrader-Frechette[2] offers an analysis of risk assessment which in many ways will form the framework for this thesis; that is, in how I will examine various examples of breast cancer risk management. She breaks risk assessment down into three different parts which each have an important role in the overall analysis of risk. These three elements are as follows:

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[1] Three articles which provide an example of this work are: Conrad Brunk, et al., "Is a Scientific Assessment of Risk Possible? Value Assumptions in the Canadian Alachor Controversy", *Dialogue* XXX (1991), p. 235-47; Carl F. Cranor, "Some Moral Issues in Risk Assessment", *Ethics* 101 (October 1990), p. 123-143; Sven Ove Hansson, "The False Promises of Risk Analysis", *Ratio (New Series)* VI (1 June 1993), p. 16-26.

[2] The following explanation of Shrader-Frechette's work is based on: K.S. Shrader-Frechette, *Risk and Rationality*, (Berkeley: University of California Press, 1991). See especially p. 5, 9, 12, 40-43, 68.

(1) Choice of topics - What should be looked at? What do we need to know the risk of? Decisions here will ultimately rest in many ways on one's view of eg. society, disease, and culture. These can be considered as contextual values. For example, it has been show that "generally women's health issues have been ignored in the U.S. and other countries"[3]. The funding statistics for breast cancer research seem to back this claim up:

> Breast cancer accounts for 32 percent of cancer incidence in women and 16 percent of all cancers, but breast cancer has not received as much attention as cancers of the lung, colon, and prostrate, which predominantly strike men. The [American Cancer Society] spent only 4.5 percent of its $380 million 1992 budget on breast cancer research; the [National Cancer Institute] allocated only 10 percent of its $2 billion 1993 budget.[4]

One can question these funding decisions and will most likely find that certain values are used to prioritize diseases and to determine their funding. It seems from these statistics, that breast cancer has not been high on the priority list for research.

(2) Methods, procedural considerations - What data is relevant? Do we have enough of it? Which statistical tool should be used? Shrader-Frechette places an emphasis on the values which come into play here; science cannot avoid making methodological value judgements. This awareness is important because most of these value judgements are typically ignored or not recognized. There are many gaps in scientific knowledge; how

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[3] Ruth Macklin, "Women's Health: An Ethical Perspective", *The Journal of Law, Medicine, and Ethics* 21(1), (Spring 1993), p. 23.

[4] Monte Paulson, "The Politics of Cancer", *Metro Times*, (May 19, 1993).

one decides to deal with these gaps and uncertainties relates very closely with what one believes qualifies as "good" science or "proper" procedure. These decisions in turn overlap onto the contextual values mentioned in (1).

> In the past, researchers have restricted their studies to male subjects and then generalized their results to women. The underlying assumption has been that etiology, diagnosis, and effective treatment are unrelated to a patient's sex.[5]

This procedural assumption has been called into question as of late, especially with the well-known case of women and heart disease. As the incidence of heart disease has increased in women, we have become aware of the fact that many women present with different symptoms and indications of heart trouble as compared to the standard ones for men. For example, rather than having the sharp pain in the left arm or shoulder, a woman may experience vague discomfort or a feeling of heaviness in the chest area[6]. This example indicates the need to revise the above-given methodological assumption for research.

(3) Evaluation - Is this risk minimal? Is this risk below acceptable standards? Is this a risk I need to be concerned about? Should I do something about this risk? Can I alter this level of risk? Many types of values come into play at this level. These can range

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[5] Susan Phillips, "The Social Context of Women's Health: Goals and Objectives for Medical Education", *Canadian Medical Association Journal* 152(4), (Feb. 15, 1995), p. 508.

[6] For more on this, see: Edward B. Diethrich, M.D., and Carol Cohan, *Women and Heart Disease*, (New York: Ballantine Books, 1992).

from personal to social to cultural values and involve emotions. It is questionable whether one can make decisions on risk without the utilization of some value structure. Values are more commonly recognized as being involved at this level as this is where much of the controversy over risk assessment is typically found. One example of the controversy which can develop over the acceptability of risk, and the various forms of risk that may be involved, is the genetic test for the BRCA1 mutation. Advocates of the test say that it can give peace of mind to those who find they don't carry the gene. Critics of this test argue that the risks, for those who do carry the gene, outweigh this peace of mind. There is little to offer to those who test positive for BRCA1 in the way of prevention. As well, there is the possibility of insurance and employment difficulties. While this test has been approved for commercial use in the United States, it currently has no application for use in Canada (outside of research). The outcome of this debate will depend on the balancing out of these mentioned risks (plus others). This will not be an easy task as the benefits and risks of the genetic test can change depending on who is doing the risk evaluation[7].

I believe Shrader-Frechette's analysis is useful in that it expands our understanding of the role of values at each level of risk assessment and can allow a more complete analysis of controversies in risk.

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[7] These ideas are gathered from: Dennis Bueckert, "Toronto Researchers Offer Women Controversial Cancer Testing", *Ottawa Citizen*, (Tues., Feb. 20, 1996), p. A5.

CHAPTER TWO: RISK DISCOURSE IN BREAST CANCER

I have claimed that, (1) values are present in risk assessment, (2) the dominance of certain values in breast cancer risk discourse have led to a narrow and biased focus of this disease's management, and that (3) there are other values which should have a role in breast cancer risk assessment and can challenge the narrow focus. In order to demonstrate these points, I have chosen five different areas for the analysis of values in breast cancer risk discourse. These are: mammography; prophylactic mastectomy; the tamoxifen prevention trial and associated topics of hormonal replacement therapy, the "Pill", and the role of estrogen; research routes; and prevention of breast cancer. The fourth and fifth topics are closely related. Both will begin to draw out and formally identify the different value structures which can operate in breast cancer risk assessment as well as indicate how the alternative risk discourse can widen the scope of breast cancer risk management.

One of the first things science tries to do when faced with a new disease is to discover its cause. Once this is established, a route for finding a cure can be followed, rather than simply treating a patient's symptoms. One of the main clues to a disease's cause is its associated risk factors. The observed correlations between a disease and certain characteristics in the people who suffer from it, can many times provide important information on a disease's etiology. Sometimes though, the path to finding the cause is frustrating and takes a very long time to complete. With some diseases,

the cause has yet to be found, despite much time, effort, and money. This latter situation typifies breast cancer. Many risk factors have been identified for breast cancer, yet its cause or combination of causes has not yet been found. We are still unsure of how a person develops this disease. Thus, the discussion of risk takes on special meaning; all we can discuss for women is the chance of developing breast cancer and the possible ways we may be able to alter these chances based on our hypotheses of how this disease develops. As we will see though, there is more than one way of identifying and dealing with these risks in breast cancer.

As I have previously stated, I believe there are some fundamental problems with the way in which risk is defined and communicated among the different groups involved in breast cancer. In each of the following sections, with the use of Shrader-Frechette's model, I aim to: first, describe the current situation as accurately as possible, second, point to the problems I see with this situation, and third, identify the underlying divergent values which lead to this questioning and, where appropriate, attempt to show what a revised version of risk would add to this picture. This will commonly take the form of including other factors, such as environmental or psychological aspects, for consideration in the risk assessments.

In, *Media Advocacy and Public Health*, L. Wallack, et al., state that "how we define a problem determines its solution"[1]. This is a fairly common concept, but they

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[1] L. Wallack, L. Dorfman, et al., *Media Advocacy and Public Health*, (Newbury Park: Sage Publications, 1993), p. 10.

add to this concept by indicating that this crucial act of definition relies on a particular analytical perspective and that this perspective commonly remains invisible. I want to make the perspective for the definition of risk in breast cancer visible for us to examine and to show that a new perspective can and should be articulated to the benefit of all affected women.

Section 2.1: Mammography

Much attention has been focused on mammography in the last few years due to the controversy surrounding the usefulness of this procedure in reducing breast cancer mortality - especially in women aged 40-49 years. This controversy arose mainly out of the results of the Canadian National Breast Screening Study which suggested that there was no benefit from mammography for this age group[2]. Previous to these results, recommendations were such that women aged 40-49 should consider and/or start having regular mammograms. The uproar and vigorous attacks on this most recent data by both the medical profession and the lay public gives us an opportunity to examine the risk evaluation of mammography. I will examine three facets of this risk evaluation; namely, the confusion between screening and prevention, the implication of cure, and the balancing of risks and benefits from population and individual perspectives.

The difference between screening and diagnostic mammography needs to be

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[2] See footnotes 6 and 7.

clear for this discussion. When a lump is felt in a woman's breast, mammography aids in diagnosing what this lump is. Thus, the benefits of mammography as one step in learning more about a suspected cancer are clear. On the other hand, the benefits of screening mammography are more difficult to determine. Screening is a "means of accomplishing early detection of disease in asymptomatic people"[3]. For women over the age of fifty (or after menopause)[4], the benefits of screening mammography have been shown. An estimated reduction of one-third in mortality from breast cancer is possible in this age group as breast cancers which are caught early (even before being detected manually as a lump) typically have a better chance of cure[5]. It is screening mammography with which this section is concerned.

Screening is also distinct from prevention of disease. As the above-given definition of screening indicates, a screening test tries to detect disease in individuals before any symptoms are present. This is not the prevention of disease, as prevention means that some measure will be taken to try to ensure that people will not even "catch" the disease in the first place. An analogy can be made which should help in understanding this distinction. Regularly brushing one's teeth with a fluoride toothpaste

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[3] PDQ Supportive Care/Screening/Prevention Information, "Cancer Screening", *CancerNet*, (United States: National Cancer Institute, May 1995).

[4] Breast density greatly affects the usefulness of mammography. After menopause, women's breasts become less dense gaining more fatty tissue which makes the detection of lumps easier.

[5] Cancer Facts, "Breast Cancer Screening", *CancerNet*, (United States: National Cancer Institute, 1995)

and flossing should help to prevent cavities while the X-rays taken at the dentist's office are used to screen for or detect cavities before they get too big and cause pain. The difference between measures which are preventative and those which are for early detection is not always articulated and as we will see shortly, this confusion between the two terms can be found in discussions of mammography.

Why is there controversy about the NBSS study results for women aged 40-49? These results go against the prevailing opinions of both the medical profession and lay population. Dr. Cornelia Baines, Deputy director of the NBSS, has the following comments,

> ...so great is the fear of breast cancer that has been instilled (often with the best intentions) in North American women, and so prevalent is the belief in technological solutions to human problems that it seems unlikely that the demand for mammograms in inappropriately aged women will diminish.[6]

> NBSS results were unwelcome in a milieu where the lay public believes that "early detection" of breast cancer does - rather than may - lead to cure, where the media have focused on the risk of breast cancer in the young...[7]

These comments help to illuminate the lay populations' reasons for questioning the study.

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[6] Cornelia Baines, "A Different View on What is Known about Breast Screening and the Canadian National Breast Screening Study", *Cancer* 74(4), (1994), p. 1210.

[7] Cornelia Baines, "The Canadian National Breast Screening Study: A Perspective on Criticisms", *Annals of Internal Medicine* 120(4), (1994), p. 328.

As Dr. Baines points out, the lay perception of mammography typically confuses the difference between screening and prevention and believes mammography should (help) cure women of breast cancer. Much of the advertising surrounding mammography almost implies that this is the case[8]. It is important though for women to realize what having a mammogram actually means - one does not have a detectable breast cancer at this point in time and that a mammogram does not prevent one from developing breast cancer. The false sense of security created by not having the purpose of mammography clear, may result in a lax attitude towards monitoring one's breasts and/or reporting any changes in one's breasts as "my mammogram was fine last year".

The implication of a cure, if breast cancer is found by having a mammogram, also results from the publicity encouraging women to have this screening test. While the five year survival rate is dramatically improved for breast cancers which are detected early (approximately 90% survival for non-invasive cases[9]), this does not mean that any individual woman will be cured. Also, having a mammogram does not guarantee finding an early non-invasive tumour - the cancer could have already spread to the lymph nodes or into the rest of the body. While these two examples are not the majority of cases, women need to be aware of these possibilities when deciding to

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[8] These ideas are gathered from the following sources, Claire Hoy, *The Truth About Breast Cancer*, (Toronto: Stoddart Publishing Co., 1995), p. 121-152 and Deborah Lupton, "Femininity, Responsibility, and the Technological Imperative: Discourses on Breast Cancer in the Australian Press", *International Journal of Health Services*, 24(1), (1994), p. 73-89.

[9] See footnote 5.

have a mammogram.

This implication of cure also has another feature which needs to be mentioned. As Maureen Roberts, former clinical director of the Edinburgh Breast Screening Project, indicates, there is a subtle pressure on women whose cancers are discovered by mammography to be grateful to medicine and its technology for the news. How does this affect a woman's response to the news that she has breast cancer and her manner towards the medical profession? Does she become more passive and accepting of medical direction or does she resent the fact that she has breast cancer because she did as she was told and had her mammogram? Also, if this woman experiences a recurrence, what will her attitude be as she was "almost promised (if only by implication) a good outcome if [she] attended for screening"[10]? Very little is known about these potential responses of women and this is perhaps something women should demand to know more about, i.e. the psychological effects associated with mammography and being diagnosed with breast cancer.

This question of adequate information on the individual effects of mammography is important. Throughout this section, I have been making claims about the benefits of mammography; these benefits are established at a population level. Certainly if from population studies, mammography is found to decrease mortality for a certain age group, this means individual women are being benefitted. But this is a

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[10] M Maureen Roberts, "Breast Screening: Time for a Rethink?", *British Medical Journal* 299, (1989), p. 1154.

benefit calculated solely by improved overall survival rates. Should this benefit be paramount over all other possible considerations? This form of analysis ignores many of the factors which could come into play at the individual level about the benefits and risks of mammography. Other factors which may influence a woman's decision to have a mammogram, beyond the possible benefit of increased chance of cure, include: the possible physical pain caused by the procedure, the anxiety created by false positive results and the need for further intervention (false positives will increase when a woman's breasts are dense), the possibility of false negatives (which also increase with dense breasts), and exposure to radiation (low dose, but potentially damaging)[11]. As Deborah Lupton pointed out in her study of the (Australian) press discourses on breast cancer, very little mention was made of the anxiety which can be caused by this procedure and whether it is proper for healthy women psychologically to experience this anxiety[12]. As well, the options of self or clinical breast exams were rarely mentioned. Personal responsibility for catching breast cancer early focused mainly on mammography; this could then conceivably limit a woman's perceived options for an active and informed role in her own health.

As hinted at by Dr. Baines above, the media portrayal of mammography is also important in another way. The accompanying pictures for discussions of breast cancer

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[11] Susan Love, *Dr. Susan Love's Breast Book*, (Reading, Massachusetts: Addison-Wesley Publishing Company, 1995), p. 255-260.

[12] Deborah Lupton, p. 85.

and mammography usually show young women - perpetuating the idea that young women should be concerned about breast cancer. At the same time, the use of young women in these photos does not allow for explicit targeting (visually) of the older women who could actually benefit from mammography. Older women, simply by getting older are at a higher risk of breast cancer, and mammograms have been shown to aid in catching breast cancer early enough in this age group to improve their survival rates. Young women are fed the messages, creating both anxiety and the demand for mammograms despite the lack of proof of benefit[13].

One possible explanation for this portrayal of younger women is that breast cancer in premenopausal women is frequently more aggressive and has lower survival rates[14]. Thus, medicine may feel that screening should be utilized for this segment of the population to try to catch these cases (despite the lack of evidence on mammography which supports this move). The desire to offer every possible avenue for "prevention" or catching this disease early is a commendable attitude, but misplaced if there are no benefits for and possibly even greater risks (including potential psychological and physiological damage) for young women having mammograms. Could it come down to an inability of the medical profession to admit that its previous recommendation about mammography was wrong and/or that it does not know the cause of this disease? As it currently stands in the United States, the

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[13] *Ibid.*, p. 84-85.

[14] Susan Love, p. 348.

National Cancer Institute has changed its guidelines to reflect this new data while the American Cancer Society still recommends that 40-49 year old women have mammograms. This conflict in policies (without explanation other than referring to the adequacy of data) serves only to make it more difficult for women to know what the right decision is for them on mammography, as even the "experts" are in disagreement.

I believe this examination of the risk evaluation of mammography has indicated that there are different values which are being used to either recommend or question the usefulness of mammography for (mainly) women aged 40-49 years. As identified, the value of technology is central to this debate. Technology is here portrayed as leading to the cure and/or prevention of breast cancer. Another closely connected value is the technological imperative: "if we have the technology, we should use it". This value places doing everything possible over recognizing the limitations of the given technology. Part of this recognition and enforcement of limits could be based on considering the individual persons affected, such as by taking into account the psychological effects of mammography. The facts we have for risk evaluation are from population studies and only address the effects of mammography on survival rates. Little is known about the individual risks and benefits of mammography. Should the value of technological application, especially if questionable, dominate over attention to the possible damage this technology could create? Perhaps this narrow focus on early detection and cure has caused both medicine and the lay population to neglect

these other considerations.

Section 2.2: Prophylactic Mastectomy

Prophylactic mastectomy, or preventive mastectomy as it is sometimes called, is surgery to remove one or both breasts of women who have strong risk factors for breast cancer, but no evidence of this disease. The estimation of this risk is influenced by a variety of clinical factors including family history, a prior history of breast cancer, presence of carcinoma in situ or benign proliferative lesions (these are not actually forms of breast cancer, but show a propensity for abnormalities within the breast tissue), the ease with which the breasts can be evaluated by physical examination and mammography, and the individual woman's perceptions about her own breast or breasts. Drs. Wise and Johnson, in their book *Breast Cancer: Controversies in Management*, state that prophylactic mastectomy should play a small role in the management of breast cancer and should not be entered into without a full description of a patient's risk profile and even perhaps a psychological assessment of the patient[15].

From this seemingly neutral description, one may wonder why there is debate among medical professionals and the community about this form of surgery as a preventative measure against the risk of developing breast cancer. Through the

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[15] Leslie Wise, M.D. and Houston Johnson Jr., M.D., *Breast Cancer: Controversies in Management*, (New York: Futura Publishing, 1994), p. 276.

following discussion, I will identify three important reasons which show why prophylactic mastectomy is actually a highly questionable procedure. These value-based reasons are a combination of both procedural (eg. determination of individual risk) and evaluative (eg. prophylactic mastectomy has some benefit) aspects. Yet despite this uncertainty about the procedure, prophylactic mastectomy is being offered by many doctors and being sought after by many women. Why? I will offer three different reasons which seem to form the crux of this "desire for surgery".

The first reason for questioning the use of prophylactic mastectomy relates to the uncertainty about the risk factors for breast cancer; the designation of a person as being high risk and therefore warranting this surgery is fraught with problems. How is the designation of "high risk" arrived at for a woman considering prophylactic mastectomy? One would assume that one or more of the presently known risk factors (see Appendix A) would have to be present in that individual. But these risk factors only account for approximately 30% of all breast cancer cases[16]. Therefore, is this designation of high risk accurate? It really only means that one is high risk according to these currently known factors which do not account for 70% of breast cancer cases. Being "high risk" does not seem quite so devastating when framed in this manner, as there could be other currently unknown factors which could play an even greater role in one's level of risk. As well, there are many other women who will develop breast

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[16] Craig Henderson, "Risk Factors for Breast Cancer Development", *American Cancer Society*, (United States: Professional Education Publication, March 15, 1993).

cancer and yet never have been identified as being at high risk.

There is also the additional difficulty of translating population statistics into individual statistics; we never really know how the different risk factors actually apply in individual patients[17]. How accurate then is our designation of high risk? Even if I have tested positive for BRCA1 and all of my female relatives have breast cancer, this does not necessarily mean I will get the disease. Thus, even from the medical point of view, it would seem that the justification for having a prophylactic mastectomy is on shaky ground - depending on how one interprets the risk factor statistics. If one places a strong belief in how one's risk profile is determined, this may provide more motivation for a "high risk" woman to proceed with a prophylactic mastectomy.

A second reason why much debate surrounds prophylactic mastectomy is that while it is portrayed as a "risk reducer", there are no studies which have shown that this is indeed true[18]. The common perception is that the degree of risk can be directly affected by the amount of breast tissue present. Wise and Johnson point out that this perception is not completely correct; despite having a total mastectomy which removes the breast(s) as fully as possible, some breast tissue will inevitably remain and this tissue could still become cancerous. It is not possible to "get" every last breast cell and therefore one's risk is not completely eliminated. No controlled study has been undertaken to show whether prophylactic mastectomy has an effect on the future

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[17] See Appendix B, footnote 5.

[18] Leslie Wise and Houston Johnson, Jr., p. 272, 273.

development of breast cancer and/or survival rates (for those women who have already had breast cancer). Therefore, the benefit for a person who undergoes this procedure is unknown when one considers solely one's risk profile. Also, given the fact that some breast tissue will most likely remain and the fact that a woman undergoing prophylactic mastectomy is or should be high risk, this surgery does not negate the need for long-term follow-up. This woman will still need to perform BSE (breast self-examination), get regular check-ups from her physician, and possibly even have mammograms. It is essential for the patient to realize that she still is at some level of risk of developing breast cancer after surgery. The emphasis on follow-up is even more crucial given the fact that if any tumour does develop, it will be closer to the chest wall increasing its probability of metastasizing into the body.

The invasiveness of this procedure on a woman's body is the third reason for questioning the appropriateness of this surgery. How often does the medical profession suggest removal of an otherwise healthy part of one's body simply because it may become diseased or cancerous? Why is this happening in breast cancer when it rarely occurs in other diseases? I believe there are two distinct, yet related, answers to this second question. The first one is based on the medicalization of risk.

> ...until the different dimensions of risk are fully recognized and made legitimate, clinical control over the uncertainty through the medicalization of risk will only increase.[19]

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[19] Sandra Gifford, Craig Janes, and Ron Stall, *Anthropology and Epidemiology-Interdisciplinary Approaches to the Study of Health and Risk*, (Boston: D. Reidel

> ...the patients undergo medical procedures that are potentially dangerous or unnecessary, even though none of the patients is sick. Marc Micozzi, M.D., Ph.D., director of the National Museum of Health and Medicine and an authority on diet and cancer, calls it "the medicalization of prevention". With this approach, doctors tell their patients, "Detecting-and treating-diseases at their earliest stages may save your life."[20]

Whether it is termed medicalization of risk or of prevention, the values are common. These are the values which place as paramount the new technologies that allow us to discover information about the etiology and development of disease and to intervene at earlier stages of disease, even before a disease occurs (i.e. when one is at risk). This implies that because we have the means of intervening and potentially altering a person's risk profile, even before the disease has started, we should do so. While in the case of high blood pressure, the decrease in risk of heart disease seems to justify medication and/or diet changes, is the same justification present for prophylactic mastectomy?

The corresponding second answer, which may help explain this attitude, lies in the medical views of the body. As Susan Sherwin points out, "medical practice involves the explorative study, manipulation, and modification of the body; because under patriarchal ideology, the body is characteristically associated with the feminine,

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Publishing Company, 1986), p. 240.

[20] Adriane Fugh-Berman, "The New Dangers of Medical Prevention", *Natural Health*, (March/April 1994), p. 84.

the female body is particularly subject to medical dominance"[21]. Could medicine's valuing of active intervention combined with its view of the female body be influencing the availability of this questionable procedure? Perhaps a value structure which placed a higher value on the integrity of the (female) body and the agency of the feminine would not offer or resort so quickly to such a drastic means of attack on the risk of developing breast cancer.

Given these reasons which show that prophylactic mastectomy is a very problematic procedure, why is this surgery still being pursued and offered as a form of breast cancer management? What explanation can be found for this situation and does it provide adequate justification for prophylactic mastectomy? I believe this explanation is composed of three main parts.

One reason why prophylactic mastectomy has become more common or more commonly sought after is due to the discovery of BRCA1; a hereditary breast cancer gene which can be tested for via a blood analysis. Many women whose families seem to have hereditary breast cancer want to be tested for this gene. Media hype about genetic discoveries may have added to this desire for being tested, which even goes beyond women who have a family history of breast cancer[22]. If it is discovered that

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[21] Susan Sherwin, *No Longer Patient: Feminist Ethics and Health Care*, (Philadelphia: Temple University Press, 1992), p. 92.

[22] One article which I feel is representative of the media hype around genetics is, John Sedgwick, "Solving the Breast Cancer Mystery", *Self Magazine*, (United States: Self Magazine, October 1993).

they have this gene, many women then consider prophylactic mastectomy as a way of dealing with this news.

BRCA1 accounts for <5% of all breast cancer cases and having this gene does not necessarily mean one will get this disease (see Appendix A). Scientists do not know how this gene functions in the development of breast cancer. Given these facts, this focus on the genetic "cause" of cancer is even more unfortunate considering how few options are available to women testing positive for BRCA1 - increased personal surveillance for lumps, more visits to the doctor, and possibly a prophylactic mastectomy (which does not even guarantee a beneficial outcome). In addition, this increased attention to the genetic component of cancer draws one away from, perhaps, the more important "causes" of breast cancer, eg. the role of environmental carcinogens[23].

As indicated by one of the considerations on Wise and Johnson's list, a second reason behind the push for prophylactic mastectomy comes from the medical profession itself. This is the consideration of the difficulty of examination of the breasts. Sandra Gifford comments that the clinical management of risk can result in the physical manipulation of the body in order to create a more certain physical condition; another aspect of the medicalization of risk[24]. Dr. Susan Love backs this

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[23] Sharon Batt, *The Politics of Breast Cancer-Patient No More*, (Prince Edward Island: Gynergy Books, 1994), p.183.

[24] Sandra Gifford, p. 230.

aspect up by stating that some women are encouraged by surgeons to consider prophylactic mastectomies because it would be "easier" - easier for the surgeon who may find it difficult to examine women's breasts that are lumpy, dense, and/or scarred from multiple biopsies[25]. Yes, one can argue that if it is difficult to examine a woman's breasts, there is the chance that a lump may be missed. The question then is how often will this occur? If more time is actually spent examining the breasts, can this difficulty be overcome? As far as I am aware, there are no definitive studies which answer these sorts of questions; certainly there is no study which indicates that prophylactic mastectomy is better than having lumpy breasts. In the case of severe scarring from biopsies, it may be felt by the doctor that a prophylactic mastectomy would help avoid the missing of lumps due to scar tissue and that a woman in this situation may actually prefer to have her breast(s) removed, rather than to continue undergoing biopsies (which cause great anxiety as one waits for test results) and that perhaps not having the breast would be better than having a greatly scarred one (although this may be different from the patient's perspective). This discussion really shows how in many ways the evaluation of risk can be skewed toward the doctor's point of view; what about the values of the patient?

Perhaps the doctor is motivated to pursue the option of prophylactic mastectomy "just to be on the safe side". But considering the degree of uncertainty about the benefits of this operation, this justification is unsatisfactory. If the risks

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[25] Susan Love, p. 246.

associated with lumpy breasts were properly understood by the affected women, perhaps they would instead demand more time be spent on "surveillance" of their breasts and on pursuing other options, such as improved diagnostic techniques.

I certainly believe it is very suspect for a physician to recommend or suggest such surgery without the patient's initial expressed interest as this decision is of a very personal nature, especially when the consideration is ease of examination. Some women do find examining their own breasts difficult and due to high levels of anxiety about breast cancer would prefer to have them removed. Other women prefer to keep their breasts and opt for close follow-up, while others carry on on their own, and still others completely ignore the risks. It seems though that for many women, concern about performing BSE properly is closely linked to the level of anxiety they experience about the possibility of developing breast cancer. This anxiety, which is one of the fundamental reasons why women pursue having a prophylactic mastectomy, is involved in many aspects of this discussion and forms the third part of the explanation for this surgery I wish to analyze.

Lesley Fallowfield, in *Breast Cancer*, reports on psychological and sociological studies which indicate that there are many lay misconceptions about the risk of cancer generally and specifically about breast cancer[26]. The lay population frequently overestimates the mortality figures for cancer at all sites and underestimates survival

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[26] Lesley Fallowfield with Andrew Clark, *Breast Cancer*, (London, Great Britain: Routlege, 1991), p. 18-20.

rates. Women also hold many mistaken beliefs or popular myths about how one gets breast cancer, eg. that bumps or knocks to the breast will result in cancer. Women depend mainly on newspapers, medical reports, special interest groups, and advertisements to inform them of the different statistics of risk for breast cancer and these are often misleading, contradictory, and frightening[27]. As a result, many women are under the impression that they are at high risk for developing breast cancer and are fearful about this possibility. These studies highlight one source of anxiety and misinformation which may contribute to a woman's decision to have a prophylactic mastectomy. Additional sources of anxiety could include the labelling of women who get breast cancer as failures - failures for not having caught it sooner or changing their lifestyle accordingly (this will be brought up more in Section 2.5) and the myth that medicine can "cure all" with its drugs and technological interventions.

Many women depend on their doctors' interpretation of the risk figures for guidance and as many feminists have pointed out, the "doctor knows best" attitude is still very strong. As Sue Fisher says, the patient is in a difficult situation.

> She has limited abilities to assess the medical knowledge and technical skill of her physician, to evaluate information, or to question the need for medical procedures, yet she is dependent on her physician's

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[27] National Women's Health Resource Centre, "Making Sense of the News about Breast Cancer", *National Women's Health Report*, (Washington D.C.: National Women's Health Resource Centre, Sept/Oct 1992). This comment on how women learn about breast cancer is not meant to be to the exclusion of other diseases nor to say that only breast cancer information is contradictory, but simply to draw attention to the fact that this is the case within breast cancer risk discourse.

> judgement. This judgement is often abstracted from the daily lives of women and is frequently coloured by traditional assumptions about appropriate roles for women in today's society.[28]

This is one case though where a doctor probably doesn't know much more than the well-informed patient. It is possible then that many women are having prophylactic mastectomies on their doctors' advice - advice which may be suspect in its origin due to the use of a value structure which does not necessarily take into account the patient's values. For example, that value structure may lead the doctor to recommend prophylactic mastectomy for a woman who is very anxious about the possibility of developing breast cancer as a method of placating that patient and making her "feel better", without taking the time to ensure she fully understands the uncertainty surrounding this operation.

The question of whether or not a patient demanding a prophylactic mastectomy should be allowed one, even if she is not at high risk, but has great anxiety about the possibility of developing breast cancer, is very important. This is when the requirement for a psychological assessment of the patient, medically speaking as Wise and Johnson have indicated, becomes necessary. Does a woman considering this type of surgery have a psychological problem? This perception places the patient more securely into the doctor's hands as he or she gains control over whether or not the patient is deemed fit to have or request this surgery. The psychological assessment can

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[28] Sue Fisher, *In the Patient's Best Interest-Women and the Politics of Medical Decisions*, (New Brunswick, New Jersey: Kutgers University Press, 1986), p. 4.

give the doctor information on the amount of anxiety a woman is experiencing, how much of a role this is playing in her decision, and whether or not she will be able to cope with the loss of her breast(s). But once again, this psychological testing gives power over to the physician who will have the final say on what the risk profile for a given patient is (this time I am including the psychological risks) and if the surgery should be performed.

Should prophylactic mastectomy be an option in the management of breast cancer? From the medical perspective, I believe that this is a blatant admission of the failure to find either a cause or a cure for this disease. Prophylactic mastectomy is typically regarded as a preventative measure against getting breast cancer, but as I believe I have shown, this claim is not founded. There are both procedural problems (eg. no studies showing a reduction in the occurrence of breast cancer) and evaluative problems (eg. anxiety as a factor in the decision to have a prophylactic mastectomy) with this procedure. Medicine is offering, and women are seeking, a technological solution to breast cancer risk without fully evaluating the drawbacks to this procedure and the message it is helping to perpetuate. This message is that technology can cure (even when this claim is unjustified) and that people should pursue the technological option despite personal costs.

Section 2.3: Tamoxifen Prevention Trial and Associated Topics of Hormonal Replacement Therapy, the "Pill", and the Role of Estrogen

I have chosen to address these four topics together for the following reason; as will become apparent, because each of these topics circles around the question of estrogen's role in the development of breast cancer, they all raise similar, and possibly the same, philosophical questions with respect to risk. I will show that the narrow interpretation of risk as per estrogen has greatly increased research into all phases of a female's reproductive life and the potential for much greater future manipulation of these phases exists. This narrow focus has at the same time marginalized environmental research and continues to basically ignore external sources of estrogen (chemicals which mimic or have estrogenic properties) that may have a role in causing breast cancer. A refocusing of risk discourse is needed to rectify the lack of research into these ignored areas and to prevent the dangers of this current "obsession" with estrogen.

I will open this discussion with an analysis of the tamoxifen prevention trial. First, I will briefly give the scientific background for this trial and then second, present three concerns about the trial which all deal with the topic of risk. Two of these concerns are procedural while the third questions the involved risk evaluations.

Tamoxifen[29] (produced by Zeneca Pharmaceuticals under the tradename

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[29] Most of this basic information on tamoxifen is taken from: Nancy E. Nazari, M.D., *Letter from Zeneca Pharmaceuticals Concerning Tamoxifen*, (Wilmington, DE: Zeneca Pharmaceuticals Group, 1994).

Nolvadex) is a drug which was developed initially for the treatment of advanced breast cancer, mainly in those women whose tumours are estrogen-dependent, and has been lately shown to be successful as an adjuvant therapy. The chemical structure of tamoxifen is similar to that of estrogen. It can therefore mimic estrogen and block this hormone's binding to the tumour cells in the breast, thereby decreasing the tumour's rate of growth or interfering with its replication. Tamoxifen is anti-estrogenic in the breast, while in the rest of the body it acts like estrogen and therefore has positive effects on reducing the risks of osteoporosis and cardiovascular disease in postmenopausal women. Due to tamoxifen's success in treating women with breast cancer, its seeming preventative effect on reducing the recurrence of a patient's original tumour, and its possible prevention of the development of new cancers in the opposite breast of breast cancer patients, the Breast Cancer Prevention Trial (BCPT) has been initiated to see whether this drug can be used to prevent breast cancer in healthy women who are at high risk of developing this disease.

The National Cancer Institute has issued the following information about the BCPT[30]. There are two groups of women who are eligible to participate in this clinical trial; one, women over the age of sixty and two, women from ages 35-59 who are at high risk for developing breast cancer. Age alone is the best indicator of increased risk, therefore, women over sixty have a high probability of getting breast cancer (1 in

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[30] National Cancer Institute, *Questions and Answers: The Breast Cancer Prevention Trial*, (United States: NCI; CancerFacts, June 1995).

24 increasing to 1 in 9 by age 85). Women aged 35-59 years must have a risk of developing breast cancer within the next five years that is equal to or greater than the average risk of a 60-year-old woman. This risk is determined by a computer calculation based on the following factors:

*Number of first-degree relatives (mother, daughters, or sisters) who have been diagnosed as having breast cancer;
*Whether a woman has any children and her age at first delivery;
*The number of times a woman has had breast lumps biopsied, especially if the tissue was shown to have a condition known as atypical hyperplasia; and
*The woman's age at her first menstrual period.

OR

A woman must have been diagnosed as having the noninvasive breast cancer called lobular carcinoma "in situ", a disease that greatly increases her chance of developing invasive breast cancer.

Participation in this trial means either taking tamoxifen or a placebo (the participant does not know which she is receiving) twice a day (total dosage of 20mg of tamoxifen/day) for a period of five years. Medical tests are required before being accepted into the trial and will be repeated at intervals throughout the study. It is essential that any side-effects or symptoms be reported as soon as possible.

There are various side-effects which may be experienced as a result of taking tamoxifen. These range from nausea and vomiting to menopausal-like symptoms like hot flashes, menstrual irregularities and vaginal dryness, to the possible increased risk of endometrial/uterine cancer. There are also concerns about blood clots, liver damage, and a possible increased chance of developing liver or intestinal cancer. The

information is currently inconclusive for these last two mentioned diseases.

The first procedural concern I have about this trial is, once again, the definition of a person as being at high risk of developing breast cancer. While this trial has specified clearly the factors it is using to determine whether a woman between the ages of 35 and 59 should be included, the difficulties of translating population statistics to individual people are still present.

Tamoxifen has been promoted as a treatment drug for estrogen-dependent tumours. What this last phrase really means is that when the tumour is biopsied or excised, an estrogen-receptor assay is performed to determine the number of receptors which the tumour cells have for estrogen. This is an indirect way of learning whether or not the breast cancer depended on the hormone to grow[31]. If a tumour is found to be ER-rich (which means it has a higher number of receptors than normal cells), then hormonal therapy in the form of tamoxifen may be prescribed (other possibilities include an ovariectomy for premenopausal women) with a higher degree of success as compared to ER-poor tumours.

The procedural concern I raise here, which to my knowledge has not been fully explained by the BCPT protocol, is why the researchers are so enthusiastic about tamoxifen's possible preventative effect in premenopausal women. While approximately two-thirds of all breast cancers are ER-rich, the majority of these are

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[31] Rose Kushner, *If You've Thought About Breast Cancer...*, (Kensington, Maryland: Women's Breast Cancer Advisory Centre, 1991), p. 19-24.

found in postmenopausal women[32]. Premenopausal breast cancers are mainly ER-poor and there is currently no method to predict which high risk women, if they develop breast cancer, will be ER-rich or poor. Thus, it seems to me that the logic for including premenopausal high risk women in these studies is not completely consistent. How is a woman to balance out the risks of taking this drug with the possible risk of developing breast cancer? It seems to me to be a fairly big gamble that if one is premenopausal and may develop breast cancer that, if one does, it will be in the minority of cases which are ER-rich. This difficulty of balancing risks will be discussed more fully below.

The third concern deals with the type of prevention being promoted by this trial: prevention which is based on drug-taking by healthy women. This is based on a risk evaluation which believes that the risks posed by pharmacological intervention are much less than either other low-tech forms of prevention or simply not doing anything. This reliance on drugs, which <u>may</u> help reduce the number of breast cancer cases, nonetheless increases the dependence of women on medicine and draws attention away from other potential factors which could cause this cancer. The publicity surrounding this trial has been very widespread and positive, encouraging women to discuss with their doctors whether they are suitable candidates for the trial[33]. Dr. Adrian Fugh-

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[32] *Ibid.*.

[33] National Cancer Institute, *Questions and Answers: The Breast Cancer Prevention Trial.*

Berman states that, "the Tamoxifen and Proscar [a potential preventative drug being tested for prostrate cancer] trials point to an alarming fact: Doctors are now suggesting that simply being a man or woman puts one at sufficient risk for pharmaceutical intervention"[34].

Part of this questioning of the true "preventative potential" of tamoxifen results from the recent studies which have indicated that there may be some very serious side-effects from taking tamoxifen[35]. These include increased risks of liver damage or cancer, endometrial cancer, and intestinal cancer. Claire Hoy questions the acceptability of these increased risks; "disease substitution is acceptable in a treatment trial,...this is not acceptable in a prevention trial"[36]. I agree with this statement as these potential risks are seen from two different lights depending on whether one is being treated for a current cancer or one is completely healthy. Indeed, as many of the reports on tamoxifen state, its benefits as a treatment for breast cancer have been completely established[37]. It is the benefits as a form of prevention which need to

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[34] Adrian Fugh-Berman, p. 111.

[35] National Cancer Institute, *Questions and Answers About Tamoxifen*, (United States: NCI; CancerFacts, April 1994).

[36] Claire Hoy, p. 14.

[37] While tamoxifen has been shown to have beneficial effects for both ER-rich and ER-poor breast cancer cases in postmenopausal women, these benefits are much greater for the ER-rich group. As a result, chemotherapy is usually recommended for ER-poor cases as the first attempt at treatment. This is based on: Shailendra Verma, M.D., "The Management of Metastatic Breast Cancer", *Treating the Female Patient* 7(5), (January 1994), p. 4-13.

questioned. The great enthusiasm shown for this trial worries me in that the risks of taking this drug are being downplayed by the researchers to such a great degree, I wonder if these risks will receive due weight in the final evaluation of this drug's effectiveness. From a medical standpoint, tamoxifen may be evaluated to have a preventative effect on the occurrence of breast cancer; what values are being used to reach this decision? Is the decrease in breast cancer incidence sufficient to alleviate concerns about the serious side-effects? How would a doctor versus a woman at "high risk" evaluate the data? One may question the appropriateness of drug intervention in healthy women just to reduce the possibility of breast cancer. Various plant products (eg. soybeans) have been shown to decrease levels of circulating estrogens in women[38]. Why not recommend eating these products as a preventive measure instead of a pharmacological route?

While I do not want to detract from the potential decrease in the incidence of breast cancer which the use of tamoxifen as a preventive drug may be shown to give, I believe that the narrow focus on pharmacological manipulation of risk results in a situation which restricts, rather than opens up, the options for women. The possible reduced risks of cardiovascular disease and osteoporosis are being played up and off against the possible risks of tamoxifen's side-effects, including other forms of cancer. All of the different facets of risk which come into play in this decision need to be given their due attention. Medicine is offering what it deems to be the best solution;

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[38] Adrian Fugh-Berman, p. 112.

what women need to do is to decide whether or not they agree that tamoxifen is a suitable answer.

The next topic which I would like to discuss is that of hormonal replacement therapy - another highly debated treatment. Hormonal replacement therapy (HRT) is usually considered for menopausal women who are experiencing severe problems with hot flashes, vaginal dryness, and also for those menopausal women at a great risk of cardiovascular disease and/or osteoporosis. The hormonal replacement can be solely in the form of estrogen (single-agent therapy, ERT) or as a combination of both estrogen and progesterone. This treatment has been associated with an increased risk of endometrial cancer and a possible link to breast cancer is being researched. It is unclear what this link is, although some studies show that postmenopausal women who have taken HRT for many years (9 or more) have a higher level of breast cancer than expected. Many scientists, however, think that for most women, the benefits of HRT clearly outweigh the possible cancer risks[39].

There are two different routes for offering criticism of this "treatment" for postmenopausal women. The first is the balancing of the risks and perceived benefits of HRT while the second considers the whole attitude of the medical profession towards menopause as a disease or "estrogen deficiency" which needs to be corrected. Mixed messages can be found in the discussion of HRT denoting the different value

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[39] National Cancer Institute, *Menopausal Hormone Replacement Therapy and Cancer Risk*, (United States: NCI; CancerFacts, Nov. 1992).

decisions being made. I believe these messages cause confusion for women on what their best course of action would be with respect to the use of HRT and the risk of breast cancer.

As stated above, medical opinion is that the reduced risk of osteoporosis and cardiovascular disease is much more important than the possible increased risks of endometrial and breast cancer. It is true that many more postmenopausal women experience heart attacks and brittle bones than develop cancer, but is this an adequate justification? Are there not ways, other than drugs, which can help to reduce these risks? Weight-bearing exercise, proper nutrition, and an awareness of stress all help to keep these conditions under control before and after menopause. Is the narrow focus on the pharmacological fix of HRT preventing us from raising awareness and trying to get change in women's lifestyles (which will reduce the need for drug intervention)?

Many doctors argue that women are in an "unnatural state" after menopause, one which should be medicated. This state is spoken of as an "estrogen deficiency" which needs to be rectified[40]. In light of the focus on the role of estrogen in breast cancer, I am surprised to find that doctors are encouraging the use of HRT. On the one hand, premenopausal women are repeatedly told about the different risk factors for breast cancer which, for the most part, have something to do with the female reproductive system and one's continued exposure to estrogen. Yet, when one's

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[40] These ideas are drawn from: Dianne K. Kieren, "Women's Choicemaking About Menopause: Issues and Directions for Action", *Canadian Home Economics Journal* 45(4), (Fall 1995), p. 143-146.

ovulation stops and estrogen levels decrease, doctors want to bring these levels back up rather than celebrate the lessening of estrogen exposure. They recommend HRT on the basis of its beneficial effects on cardiovascular disease and osteoporosis and downplay the risk of breast cancer. No wonder women are confused about whether or not they should take HRT. The media hype causes premenopausal women to be anxious about the possibility of breast cancer and to be vigilant in "warding it off"[41]. Yet, when these same women become menopausal and the risk of developing breast cancer rises dramatically, this risk is downplayed in order to draw women into using HRT. I realize the balancing of risk is difficult for both the involved doctors and women, but these messages seem to be almost contradictory and can result in women's dependence on medicine for the interpretation of risk.

What values could be behind these mixed messages? I suggest that medicine's push to offer a pharmacological fix to different risks of disease women face, relies on the perceived benefit of technology. Once again, given that we have discovered these drugs, why not use them? The push is for medicine to have an active role in the patient's life; even if she is currently healthy, risk of disease lurks and "we" should do everything possible to avert the actualization of this risk by disease. What this form of risk evaluation does not take into account though is that the increasing interventions could have serious side-effects which do not warrant their use - these side-effects may not be merely biological, but psychological as well (such as the perception that one is

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[41] Deborah Lupton, p. 85-86.

a walking "time-bomb" due to being at high risk for some disease).

This confusion due to mixed messages can also be found in the discussion of birth control. One of the most well-known forms of contraception for women is the oral contraceptive or the "Pill" as it is commonly called. Oral contraceptives (OC's) were first introduced in the 1960's and were widely welcomed for their "convenience, effectiveness, and reversibility of action"[42]. The "Pill" has undergone many reformulations over the years as to the amount of estrogen used and its combination with progesterone. Concern about the link between oral contraceptives and cancer as well as other health problems has been a source of continuing debate.

Research has focused on the use of OC's and early-onset breast cancer (i.e. before menopause) due to the suspected role of estrogen in the development of this disease[43]. Various studies have looked at different age groups, age at start of use, the length of use of OC's, and use of OC's before and after pregnancy. It seems that one of the subgroups of women who are at an increased risk of developing breast cancer are females who start using the "Pill" during their teens (less than 25) and continue this usage for a long period of time. Further research has not clarified the risk situation; it now seems that increased risk of breast cancer may not be restricted to this group. Other possibilities include childless women and even those not under the

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[42] National Cancer Institute, *Oral Contraceptives and Cancer Risk*, (United States: NCI; CancerFacts, April 1995).

[43] This summary of research is taken from: National Cancer Institute, *Oral Contraceptives and Breast Cancer*, (United States: NCI; CancerFacts, April 1994).

age of 25 who are long-term users.

Possible factors affecting the results of this research are the number of reformulations the "Pill" has gone through since its first introduction to the market. Women who began taking the "Pill" in the 60's received much higher doses of estrogen than women do today. This variation makes it difficult to establish trends and compare research results. Also, there seems to be evidence which suggests that the increased risk disappears within 10 years after stopping use of the "Pill". However, the latest study reported on by the NCI "adds to the evidence that OC's increase the risk of breast cancer in women under age 35"[44] . While the above problems in interpretation of data still exist, this study sides with the evidence which indicates that there is a biological connection between use of the "Pill" and breast cancer and not simply a statistical one.

The biggest consideration with the "Pill" is how complicated its risk discourse becomes. Somehow women have to balance the risks of taking the "Pill" vs. the risks of becoming pregnant. The new research on the possible increase in the risk of developing breast cancer lends yet another dimension to this decision. If a woman is already at high risk where breast cancer is concerned, how does taking the "Pill" affect this? Currently, there is little, if any, information which can help one to make this decision - no matter what a woman decides there will be certain possible

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[44] National Cancer Institute, *Oral Contraceptives and Risk for Breast Cancer in Young Women*, (United States: NCI; CancerFacts, July 1995).

ramifications. To make matters worse, there is the prevailing attitude "that the "Pill" {and HRT} are part of a lifestyle that North American women freely embrace" as pointed out by Sharon Batt[45]. How free are these choices when there is a lack of alternative birth control methods with the same reliability as the "Pill" and birth control is typically the woman's responsibility (and when menopause has been medically defined as a condition of deficiency which needs to be treated)? While this discussion starts to draw away slightly from the interpretations of risk which I wish to discuss, it begins to show how intimately linked the definitions of risk from one situation of a woman's life to the next are and how they lend a certain "authority" to the interpretation of and solutions to the risk of breast cancer (and other diseases or problems) which the medical profession promotes. This is the narrow focus on technological fixes and individual causation which draws away from the larger picture of society's role in disease and possible changes which could be made here.

A secondary consideration is how the attention to the possible link of breast cancer and the "Pill" forms yet another route for the creation of anxiety about breast cancer risk. Despite the fact that this research may not be applicable to the "Pill" today due to its reformulations and the still tenuous link to breast cancer, a warning about the possible increased risk of breast cancer has been printed on the information sheets for the "Pill". There seems to be some basis for wondering if there is a "hidden" message behind this emphasis on breast cancer and the "Pill". Indeed, in Deborah

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[45] Sharon Batt, p. 130.

Lupton's analysis of press discourses on breast cancer and the "Pill", it was her conclusion that,

> ...ambivalence about the role of the contraceptive pill in freeing women to enter the workforce was reflected in the tendency of the press to devote dramatic headlines to the health risks of the pill, while at the same time drawing an association between the choice of a career over motherhood and the risk of developing breast cancer.[46]

One common thread throughout all of these topics is how the emphasis on the role of estrogen in breast cancer has led to vigorous research focusing on the female reproductive system and its possible manipulations to correct deficiencies, decrease or avoid other risks, or to find a balance between different desired outcomes. I think this is a "constructed research focus" based on medicine's exaggerated interest in the risks associated with a woman's normal biological cycles. While I do not want to claim that this current research will not provide useful information for women and for understanding breast cancer, it is what the assumptions behind this construction of risk and choice for risk assessment and research leave out that troubles me. What is left out are other possible research routes focusing on the same role of estrogen in breast cancer, but from an environmental and/or societal perspective, eg. the use of chemicals such as organochlorines which are known estrogen-mimickers.

The "explicit" messages given by medicine about the role of estrogen and the various topics discussed here seem fairly clear: tamoxifen is proven as a treatment for

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[46] Deborah Lupton, p. 86.

breast cancer and will most likely be the next preventative drug-its risks are minimal, HRT is highly recommended for menopausal women for its positive effects on cardiovascular disease and osteoporosis, and the "Pill" is the best birth control choice for women today. It is the subtle or "implicit" messages which are confusing for women and give a better insight into the values of medicine. These messages make women anxious about the role of estrogen in the development of breast cancer and imply that the female reproductive system is at fault. This faulty reproductive system must be manipulated in various ways to control its effects on the risk of developing breast cancer. The surprising counter-example is HRT which, despite possible increased risks of breast cancer, is recommended to avoid the risks of other diseases that are now evaluated as being more important. The risk of developing different diseases are played off on each other in sometimes contradictory manners, but the one common denominator through it all is how these manipulations of risk discourse by the dominance of the value of technological and pharmacological intervention and the perception of individual causation result in a narrow focus on the female body.

Section 2.4: The Different Research Routes

In the previous section, I stated that I believe there is a "constructed research focus" on the role of estrogen in breast cancer which in many ways directs where research will be conducted. This focus is on estrogen and the female body with little consideration of the larger environmental and social issues which may alter and affect

the levels of estrogen in a woman's system. In the first part of this section, I will highlight some of this current research and demonstrate the very real problems it could lead to for women's ability to determine how they wish to respond to the risk of breast cancer. This will clearly identify the dominant values which I have been trying to trace throughout this thesis.

The second part of this section will focus on the environmental research for which many breast cancer (and other) advocacy groups are calling. Is this approach to breast cancer viable? Is there sufficient evidence to warrant continued and more research into the wider societal causes of breast cancer? I will show that there is indeed enough evidence for this approach and will also show how even this research and risk assessment can be affected by the identified dominant values.

2.4.1: Hormonal Manipulation

One example of how the assumptions about research on the female body and the manipulation to which it can be subjected connect with the narrow focus on the role of estrogen in breast cancer is found in the projects recommended and undertaken respectively by Drs. Richard Margolese, Walter Willett, and Malcolm Pike with Darcy Spicer. Dr. Margolese has made the following comments about the increased exposure to estrogen women today have, due to their reproductive cycles, and its possible link to disease, "...[consider] how many ovulations women had [before] in their lifetimes: 30 or 40. Now you have 400 and I think that's not normal. I think we should learn about this and we should learn whether or not it is worth manipulating in some way,

in order to protect women from diseases"[47]. Dr. Willett was quoted at a conference titled, "New Frontiers in Cancer Etiology and Prevention", sponsored by the Harvard School of Public Health, as proposing "that instead of diet we should look to pharmacological fixes for breast cancer"[48]. Specifically he endorsed "hormonal manipulation", a regimen that would include treating premenopausal women with drugs to regulate their ovulation and to induce false pregnancies in teenage girls.

Drs. Pike and Spicer are currently undertaking (privately funded) research which is touted as a hopeful future method for prevention of breast cancer[49]. It attempts to manipulate the female cycle through the use of a gonadotrophic releasing hormone (GnRH) agonist with the addition of estrogen and progesterone at different times during the cycle. The details on this trial are fairly complicated, but what these women are being subjected to is a very drastic form of hormonal manipulation. This manipulation reduces a woman's ovulation to approximately three times a year. Pike blames the modern woman's "incessant ovulation" for the increases in breast cancer incidence; this forms the rationale for his research.

The question of profit is a very real factor in these trials. If shown to be successful, the potential for application or prescription of this treatment is very high.

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[47] Sharon Batt, p. 112.

[48] Susan Rennie, "Breast Cancer Prevention: Diet vs. Drugs", *Ms.* 38, (May/June 1993), p. 42.

[49] *Ibid.*, p. 42-45.

Teenage girls and women in their twenties would be the prime targets of this intervention. But there is some indication that the manipulations to which Spicer and Pike wish to subject their patients, may not be as easily done as previously thought. One main side effect of the GnRH agonist is rapidly-induced severe osteoporosis. To avert this effect, the addition of testosterone to the hormone regimen was necessary.

Many advocacy groups are very concerned about this form of research and I believe justifiably so. The four researchers mentioned here have a clear bias about what they perceive to be the cause of breast cancer - incessant ovulation and exposure to estrogen - and are directing their research to this end. On the surface, this seems the likely course for research; develop a hypothesis about the cause of a disease and conduct studies to determine if this hypothesis is true or false. But I believe these researchers are making value judgements about the causes of breast cancer and acceptable preventative measures which need to be re-evaluated.

The following judgements are the ones I believe are being used to back-up and direct this present research: medication equals prevention of disease, less drastic forms of prevention (diet) will not work, and the risks of breast cancer are sufficient to warrant manipulation of very young women's hormonal systems. What are the values behind these judgements? I want to argue that there are four main (implicit) values being used.

First is the belief in the value of technology and its successes in our health care system; the hope that this success will continue is really emphasized in this hormonal

research. Susan Sherwin points out that people's reputations and institutions' names are not built on the low-key forms of prevention of diseases (such as diet, sanitation) but on the high-technological interventions and inventions[50]. The press holds up for esteem the technological cancer breakthroughs. These are commonly the discovery of another oncogene or a better drug for killing those cancer cells. While diet is constantly talked about as a way of preventing many diseases, does it receive the same sort of attention or raise the same sort of excitement in people? A society which values technology is going to look for technological answers. Perhaps though, it is time to look somewhere else for answers, as the last few decades have not "won the war" on cancer as had been promised.

A second value inherent in this form of research is a reductionist view of disease. Susan Gifford shows that while there is a common rhetoric speaking of the holistic, multicausal approach to disease, the reductionist approach is still used in research[51]. In the case of breast cancer and these researchers, the cause has been reduced to estrogen and specifically the estrogen produced by the female body as a result of multiple ovulations. While I do not want to dispute the role of estrogen in breast cancer, I want to argue that there needs to be a wider view taken of how the levels of estrogen can be affected. Surely the increase in breast cancer incidence

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[50] Susan Sherwin, p. 172.

[51] Susan Gifford, p. 217. I realize that individual research projects can only look at one piece of the puzzle at a time. The reductionist approach I am questioning here is that of all the research taken together.

cannot be all due to a woman now having 400 ovulations? This seems unlikely given the postindustrial society in which we live replete with its manufactured chemicals and new technologies. This seems especially unlikely given the current and still increasing incidence of breast cancer[52]. As I have mentioned, and will discuss more fully below, there are many chemicals in today's world which mimic estrogen and have been shown to have an effect on the reproductive system.

Closely linked to this reductionist view of disease is one of individual causation. Sue Fisher includes the idea of individual causation in a list of factors explaining why prevention has not gained as much attention as it should from both the medical profession and lay public[53]. The notion of individual causation focuses in on short-term results, looking for the quick fix and avoids taking a long-term perspective and questioning the role of society and culture in disease.

A fourth value at play here is that of normalcy. What is normal and what is not? Dr. Margolese stated that 400 ovulations is not normal. Normal compared to what? Certainly women have more ovulations now than, say, five-hundred years ago; but were their cycles normal then? How should a female's body be designated as

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[52] Claire Hoy, p. 8. One can assume that if incessant ovulation were the only cause for breast cancer that these continually increasing incidence rates would not occur (as women have been having approximately the same number of ovulations for the last 75-100 years).

[53] Sue Fisher, p. 94. The other factors she mentions include the lack of agreement on the definition of prevention and the changes in the doctor-patient relationship this shift would cause (i.e. balance of power).

normal? In an article on the definition of child abuse, Ian Hacking talks about the metaconcept of normalcy and the role of the medical profession in shaping our ideas of what is normal[54]. What is normal is connected to what is right and what is abnormal becomes connected to what is wrong or deviant. How is the term "normal" being used in breast cancer?

One case example where the information provided to the public on breast cancer has implicit messages about the "normal" roles for women in society is found in Deborah Lupton's analysis. One of her conclusions is that dominant cultural notions of femininity are reflected in the press portrayal of breast cancer.

> ...the binary oppositions dominating this coverage drew attention to the feminine/masculine, career woman/housewife, and sterility/fecundity dichotomies, implying breast cancer was a retribution for the rejection of motherhood and the traditional feminine role in favour of material success in the working world.[55]

Without preconceived ideas of what is the "normal" occupation for women (one of being a mother and care-provider), I believe these dichotomies would not be present in articles on breast cancer. If society truly believed in the equality of women and valued our contribution in the workforce, the discussions of prevention would most likely not centre (only) around our reproductive capacities and choices about them.

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[54] Ian Hacking, "The Making and Molding of Child Abuse", *Critical Inquiry* 17, (Winter 1991), p.286-288.

[55] Deborah Lupton, "Femininity, Responsibility, and the Technological Imperative: Discourses on Breast Cancer in the Australian Press", *International Journal of Health Services*, 24(1), 1994, p. 86.

It now becomes important to ask, "Who are the ones making the decisions about research funding?" Sven Ove Hansson has these comments about choice in risk assessment research routes:

> In general, the demarcation of a social decision problem is determined by convention and/or by deliberate decisions by those who are in a position to set the agenda. Agenda-setters are often defenders of the *status quo*, who prefer narrow decision horizons that leave no scope for radical change.[56]

Women have had a very small role in this process to date and are slowly finding a voice to protest this narrow scope for breast cancer. Most breast cancer advocacy groups are strongly protesting the way in which money is currently spent on research and the focus which it promotes. These groups are asking for input into the funding process and hope to thereby redress what they perceive to be an inadequate research approach to breast cancer.

I believe it is important, as do the involved groups, for women to be represented in these sorts of decisions. There are two related reasons for this belief[57]. The first is based on the oppression of women generally in society. The cancer institutions, medical professions, and funding agencies (which are all headed mainly

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[56] Sven Ove Hansson, "The False Promises of Risk Analysis", *Ratio (New Series)* VI 1 June 1993, p. 19.

[57] The two reasons I offer of the oppression of women in society and democratic decision-making are only mentioned briefly here by way of introduction. Both of these ideas are expanded upon in Chapter Three.

by older white males[58]) will most likely value a certain approach to breast cancer, and other women's health issues, and have the power to set this agenda. As I have been indicating, this agenda may and most likely does differ from the one women would set. The second reason is the threat to democratic decision-making which exists if all the involved parties to a problem are not included or consulted. Given the nature of breast cancer, where the general fear of cancer connects with a part of the body important in society's, and specifically women's, notions of femininity and sexuality, women need to and should have a central role in the decision-making process at all levels of risk assessment. As we are becoming more and more aware, research is a social and political activity[59]. Thus, for the research process to be democratic, women deserve to have a legitimate and recognized say in the research being conducted in breast cancer.

The research focus which the breast cancer advocacy groups seem to be requesting, in my opinion, is: to adopt a holistic approach to breast cancer research (this implies looking at both environmental and societal causes of breast cancer), to look for and consider alternative forms of treatment (as the "slash-and-burn" approach does not seem to be working or improving survival rates), and to foster a participatory

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[58] Ralph Ross, *The Cancer Industry: Unravelling the Politics*, (New York: Paragon House, 1989), p. 417.

[59] Susan Sherwin, p. 173. This view is also supported by: Peter Montague, "Making Good Decisions", *Rachel's Environment and Health Weekly*, (Annapolis, MD: Environmental Research Foundation, Nov. 30, 1995).

approach in trying to understand the etiology, treatment, and psychological aspects of breast cancer. Women are asking for a new and more care-oriented approach to breast cancer (and other diseases) as opposed to the "military" approach which in many ways separates the person from the disease which is being treated (the afflicted person becomes secondary to the treatment process)[60].

One of the ways in which the different values of women's groups can be observed at work is in their strong response to the possibility of increased hormonal manipulation. While they do not dispute the fact that this may be a potential way of reducing one's risk of getting breast cancer, many of the advocacy groups are strongly opposed to this research focus in theory (as are some in the medical profession to be completely fair)[61]. While evidence does point to the fact that a woman's breasts are more susceptible to damage or to the effects of estrogen and other carcinogens during development and/or before pregnancy, does this imply young women should be exposed to these drastic forms of hormonal manipulation? Especially when our understanding of breast cancer and the female body is so incomplete, hormonal manipulation seems to be jumping to the (wrong) conclusion much too quickly. If one needs to "alter" the individual, advocacy groups indicate that they would prefer focusing on diet, exercise, and such things before turning to these forms of

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[60] This idea is suggested in: Deborah Lupton, p. 84.

[61] For an example of each respectively, see Susan Rennie and Adrian Fugh-Berman.

manipulation. The risks of these alternative forms of prevention are very low and their benefits carry over into many other areas of health. In addition, advocacy groups emphasize the fact that they want to get away from just considering the individual and want to expand the focus to include changes which could be made in the environment and society itself.

2.4.2: Environmental Research

I believe the following will show that there is adequate preliminary evidence for supporting a thesis that the cause of breast cancer is more diverse (socio-environmental) than the one commonly proposed (individually caused) and that the advocacy groups may be right in trying to encourage this wider look at the causes of breast cancer. This exploration will revolve around two different approaches to the environmental causes of breast cancer. These are the exogenous sources of estrogen and estrogen-mimicking chemicals and the number of carcinogens in our environment.

Devra Lee Davis and H. Leon Bradlow recently published an article in *Scientific American* titled, "Can Environmental Estrogens Cause Breast Cancer?"[62]. It was their conclusion that, while xenoestrogens (foreign estrogens) cannot account for all cases of breast cancer, they do represent a preventable cause. These authors gave an overview of their research in this area as well as including evidence from many other studies about xenoestrogens. A list indicates which chemicals are known

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[62] Devra Lee Davis and H. Leon Bradlow, "Can Environmental Estrogens Cause Breast Cancer?", *Scientific American* (Oct. 1995), p. 166-171.

xenoestrogens and displays them under the following headings: chlorinated organic compounds (eg. DDT, atrazine), plastics (bisphenol A), pharmaceuticals (synthetic estrogens - HRT, the "Pill"), and fuel constituents (aromatic hydrocarbons). Research has shown that these chemicals do have estrogenic properties in the body. Currently, research is being done in order to see whether they can be implicated in the cause of breast cancer; so far, DDT and some PCB's have been implicated. The authors indicate the following routes for further study:

> First, potential estrogenicity should be assessed for materials that play critical roles in our society, such as fuels, drugs, and plastics-and for any proposed substitute agents. Second, the possible effects of estrogenic compounds on the human body should be assessed. Such tests should look at the consequences of long-term exposure and of interactions of widely used chemicals. Third, use of known inessential xenoestrogens should be curtailed.[63]

Many of these compounds persist in the environment (DDT for 50 years) which also magnifies the need for us to act now on our hypotheses that these chemicals may cause breast cancer (and most likely other diseases, eg. infertility problems). Other exogenous sources of estrogens, such as the "Pill" and HRT, have been discussed in Section 2.3.

As for other chemicals causing breast cancer, the possibility is very high. Many different chemicals have been tested and labelled as carcinogens. But are the "risks" of these chemicals, as presented, true indicators of the risks of using them? The methods

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[63] Devra Lee Davis and H. Leon Bradlow, p. 172.

used to determine the carcinogenicity of chemicals is being strongly questioned. For example, most chemicals are tested individually - what of the combination effect? What about long-term exposure at low levels compared to short-term acute exposure? These questions are being asked, not only by breast cancer advocates, but also by many other concerned groups, eg. environmentalists. As Ross Hume Hall points out, women need to be especially attentive to these studies[64]. He sees a bias against female biology in the research methods; a bias which could distort how certain chemicals are assessed to be carcinogenic. Two of the ways in which this bias is manifested are as follows. First, dose-response tests are typically done on male rats; male rats are cheaper and one avoids the difficulty of female cycles. How should results from these studies be interpreted then? If male rats develop breast tumours at a certain dosage of a chemical, is this dosage relevant to women (the straight difficulties of translating data from animal studies into human measures aside)? Would it not make more sense to test the chemicals in female rats as well? Second, when science relies on known human exposures to toxic chemicals, these are usually based on workplace exposures. How many women are represented in these analyses? The exposures are typically at male-dominated sites, such as chemical plants and paint factories. This is not to say that all of the data collected to date on these chemicals is wrong, but just to draw

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[64] Ross Hume Hall, "Female Biology, Toxic Chemicals, and Preventing Breast Cancer: A Path Not Taken", presented at *The International Conference on Breast Cancer and the Environment*, (Niagara Falls, Nov 3, 4 1995), p. 4-5. Sharon Batt also talks about the bias against female biology in research, ie. viewing the 70kg male as the norm (thus a woman is a man with ovaries and a uterus), see p. 115, 136.

awareness to these possible distorting factors where women are concerned. The connection between certain carcinogens and breast cancer is unclear, but not unlikely. When one considers the fact that we do know that the breasts are susceptible to external factors during development, concern about exposure to carcinogenic chemicals seems justified. Perhaps this is another direction which prevention should take in young girls, before committing them to hormonal manipulation.

A final indicator of the role of environment and society/culture in the development of breast cancer comes from a comparison of the rates of breast cancer incidence between countries and from comparisons to immigrators[65]. Women in Southeast Asia have a breast cancer incidence rate which is one-fifth that of North American women. Yet when Asian women immigrate to Canada or the United States, their rates of breast cancer incidence slowly rise to match that of women born in these countries. The female children of these immigrators have a breast cancer incidence which is almost equivalent to the given country. This seems to be a very clear indication that the society and environment to which women are exposed plays a very important role in determining the risk of developing breast cancer. What is it about North American culture that results in higher breast cancer incidence? Various hypotheses including industrialization, chemical exposures, stress, diet (plant products vs. fat), alcohol consumption, and birth control are offered and seem to have some scientific justification. This list indicates though how many different factors may play

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[65] Ross Hume Hall, p. 2.

a role in breast cancer development and emphasizes why we should widen our research scope to be able to consider them together.

2.4.3: Conclusion

I believe this section has shown how different interpretations of the risk factors for breast cancer can lead to divergent research approaches. On the one hand, much research is being devoted to the female body and its cycles and how these can be manipulated to change the risk of getting breast cancer. This focus is based on a value structure which emphasizes the importance of technological interventions, individual causation, and a reductionist view of disease[66]. This is in seemingly great contrast to the research which breast cancer advocacy groups, and more widely other groups such as environmentalists, are demanding. We need to examine the risks inherent in our current society and look at disease from a holistic perspective. This implies a re-evaluation of how research is currently done and an examination of what values govern the different choices our society makes. As Sharon Batt asks, "...will we change the way we live or will we accept the disease [breast cancer] as the price of life in a Western industrialized society?"[67]

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[66] I realize that a reductionist view of disease could occur just as easily if one wants to examine the environment. But I see the value of individual causation connecting with that of reductionism in breast cancer to focus in solely on the female body to the exclusion of a broader picture of the environment, society, and culture within which a woman lives. I do not believe this same use of reductionism is applicable to the approach which breast cancer groups are promoting.

[67] Sharon Batt, p. 280. I believe this question is not meant to exclude other diseases which are also related to socio-environmental factors, but to draw attention to

Section 2.5: Lifestyle vs. Societal Aspects of Prevention

As the current research focus is closely connected to discussion of the prevention of breast cancer, the following is in many ways a continuation of the previous section. Aside from the extreme measures currently being researched for the prevention of breast cancer, namely tamoxifen and hormonal manipulation, what other methods of prevention are promoted? What is being emphasized to women?

As I intimated in the discussion of mammography, the definition and understanding of prevention is often obscure. Indeed, Sue Fisher states that the "definitions of prevention vary from the cure or the arrest of the disease to the identification and diagnosis of the disease to the elimination of the underlying social and individual causes of disease"[68]. The early detection of breast cancer promoted by the focus on mammography and breast self-examination has sometimes been confused with prevention of this disease. I believe it is fair to say that the medical profession and cancer establishments, as far as "prevention" of breast cancer is concerned, focus in more on the cure/arrest of disease, its diagnosis, and the individual causes. In some ways the mentality of society reflects and reinforces these notions of "prevention". As Deborah Lupton points out, scholars interested in medicine as culture challenge the view that diseases are neutral and scientific entities. These critics show that many

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breast cancer as one of them.

[68] Sue Fisher, p. 94. I personally believe that the correct definition of prevention is the last part of Fisher's quote, ie. trying to identify and eliminate the social and individual causes of a disease (see also Section 2.1).

diseases are instead realities indicative of wider knowledge, belief, and value systems[69].

Feminists and breast cancer advocates are challenging the common representations of disease. In breast cancer, the emphasis women want is on the social causes of this disease and what possibilities are present for change. Epidemiological evidence on the etiology of chronic diseases indicates that these diseases are more closely connected to socio-environmental factors than with individual factors[70]. As some view breast cancer as a chronic disease, i.e. you only have been cured of breast cancer if you die of something else, this provides a foundation for their efforts in making both medicine and society aware of the wider contributing factors to breast cancer and other diseases.

What are the most common factors promoted in "prevention" of breast cancer? The National Cancer Institute in the United States is focusing its research on chemopreventive agents (compounds which seem to aid in the treatment of cancers and may ultimately have a protective effect) such as tamoxifen, beta-carotene, retinoids, and ibuprofen and on dietary changes such as the low fat, high fibre prescriptions[71]. *Self* magazine promotes a healthy diet, moderate alcohol consumption,

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[69] Deborah Lupton, p. 73.

[70] Sandra Gifford, p. 238.

[71] National Cancer Institute, *Highlights of NCI's Prevention and Control Programs*, (United States: NCI; CancerFacts, 1995)

and losing extra weight (fat stores estrogen)[72]. These are the typical routes mentioned for prevention of breast cancer and cancer in general. According with the dominant interpretation of the risk factors for breast cancer, I agree that these are the best methods we currently have for decreasing our risk of getting breast cancer.

What is interesting for me though is the lack of mention of other routes which could be beneficial in the prevention of breast cancer. These are the socio-environmental factors. Should not such things as the following be included as part of the prevention package: putting pressure on industries to use alternative methods with less toxic chemicals, asking for research into alternative methods of birth control, stopping pollution, and trying to alter the levels of exogenous estrogens? These are only a few of the possibilities which this thesis has suggested. Compared to the narrow focus on the individual and the changes that each person can make to "cope" with the risk of developing a disease, this list requires a much broader social committment for changing the conditions in which we live and the risks we create and are exposed to every day. It is my suggestion that this is a much more forward-looking proposal than the one medicine is currently promoting and is the route we should probably choose if we are to actually prevent or at least decrease the incidence rate of breast cancer (and other diseases).

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[72] Self Magazine, "Can You Do Anything Now to Help Prevent Breast Cancer Later?", *Breast Cancer Handbook '94*, (United States: Self Magazine, Oct. 1994).

CHAPTER THREE: THE ALTERNATIVE PICTURE

I stated in the Introduction that breast cancer is surrounded by much controversy. I believe the examination of the five different examples within breast cancer have shown that this is indeed the case and that there are various reasons for this controversy. Brunk, Haworth, and Lee, denote this form of controversy as a "risk debate" and define it in the following manner:

> A risk debate is not primarily a debate between those who accept the verdict of scientific risk assessment and those who do not. It is not a conflict between those who understand the "objective" risks and those who are guided by an irrational, "subjective" perception of those risks. Neither is it primarily a debate within science itself. Rather, it is primarily a political debate - a debate among different value frameworks, different ways of thinking about moral values, different conceptions of society, and different attitudes toward technology and towards risk-taking itself.[1]

This definition of a risk debate, in essence, captures what has gone on in the previous chapter and sets the stage very nicely for a continuing discussion of the role of values in risk assessment for breast cancer.

Both Brunk, et al. and Shrader-Frechette indicate that there are dangers in ignoring what is truly at issue in a risk debate. Shrader-Frechette believes that in focusing on what science tells us or what the "objective" facts are, we lose sight of the

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[1] Conrad Brunk, Lawrence Haworth, and Brenda Lee, p. 245.

"often exploitive way in which technology is used and [at the same time] condone a passive acceptance of the status quo"[2]. How one proposes to resolve the risk debate is another source of danger. If one leaves the determination of risk to the analysts and scientists in hopes of gaining the "objective" account, one quickly forgets or doesn't realize that this means the scientific or medical value framework can become "disguised as politically and morally neutral"[3]. Risk assessment without this guise can be recognized as value-laden and thus requiring special attention. I have given this special attention to the risk debates in breast cancer by identifying the differing involved values. This need for special attention to risk assessment in breast cancer is also generated by another perspective; this perspective comes from feminist theory.

The feminist perspective is appropriate for use in this thesis in several different ways: one, since breast cancer is a disease which attacks (mainly) women at a very important site of the body in terms of self-image, a look to feminist theory is necessary; two, breast cancer has been spoken of as a feminist issue and various breast cancer advocates rely on feminist theory as a foundation for their criticisms of breast cancer risk management and the medical system (including the cancer and research establishments); and three, feminism itself encourages us to analyze medicine and to question its role in both our health and our society.

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[2] K.S. Shrader-Frechette, p. 98.

[3] Conrad Brunk, et al., p. 245.

> Medicine has become one of our most powerful and significant institutions; generally it is treated as an unqualified good, because it is almost universally regarded as the best instrument for protecting and restoring health...[Medicine's] view of reality is seldom challenged, even when the subject matter on which they speak is beyond their scientific evidence. Their attitudes toward the human body have gained preeminence in the culture; medical values help construct people's experience of their own bodies...Human beings have learned to regard their bodies as potential sites of disease or organ breakdown.[4]

Thus, the medical establishment serves both as an institution which helps to shape and direct society's values and as an institution which reflects society's conceptions. Given women's greater use of the health care system, especially for reproductive processes and problems[5], medicine is an appropriate area to undertake a "feminist investigation". Secondly, the historical oppression of women by medicine has been well-documented, emphasizing the need for a revisioning and restructuring of health care. Thirdly, ethics, as a philosophical topic of study, is concerned with value questions about human conduct. Susan Sherwin concludes that a feminist ethics of health care must be self-consciously oriented to investigating the practices of health care with respect to the overall power structures of dominance and subordination[6].

Two factors, which help to form the basis for the conclusions I draw in this

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[4] Susan Sherwin, p. 5.

[5] K.S. Ratcliff (ed.), *Healing Technology-Feminist Perspectives*, (Ann Arbor: The University of Michigan Press, 1989), p. 180.

[6] Susan Sherwin, p. 35, 42.

thesis, come out of this introduction to the feminist investigation of medicine and use of the feminist perspective in this thesis. These are in connection with the focus in risk assessment upon values and the necessary recognition and inclusion of different value structures and judgements in resolving risk debates.

The first is that the criteria used for an analysis, such as this, must address whether or not oppressive circumstances limit input from segments of the population. Dr. Susan Love, a well-known breast cancer specialist and activist, claims that the reason more is not known about this disease is because, in part, "it is a women's disease, and women have been so well socialized to be good little girls and not to demand more attention"[7]. It seems that this silence is now being filled by the many women who are speaking out about breast cancer and are demanding political action. Yet while some women are vocal, others still remain silent. I realize that the alternative values and options I raise in these debates about breast cancer risk are influenced by what women's advocacy groups and feminist theorists are saying. It is my hope though that the offered analysis has not been completely biased in favour of these vocal women. I do believe that what I offer can be of use to both "vocal and silent" women. By demonstrating how the values which many women hold are not part of the (mainstream) risk discourse in breast cancer and by proposing routes for change, the possibility of improved health care for all affected women exists.

The second factor is that of decision-making. The question of the "right"

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[7] Susan Love as quoted by: Claire Hoy, p. 276.

treatment for a patient is not a question that can be completely answered by science or by doctors because it also involves weighing the patient's own evaluations of the risks and benefits she perceives. The experience, knowledge, and culture of a woman all shape what decision she deems to be best in her given situation. As many feminists have pointed out[8], the view of people as autonomous, self-interested decision-makers is hopelessly inadequate for many women. Women are the main care-givers in society; women care for elderly parents, spouses, and children taking on many responsibilities outside of their own individual needs. A woman's decision, for example, on treatment for her breast cancer will most likely not focus only on the "best" procedure as per survival rates, but also on how much hospital care it will require, how long it will take, and how well she will be able to function while undergoing treatment. As many doctors typically place cure or attack on disease as the primary value for consideration (such as I indicated in the section on prophylactic mastectomy), the potential for different conclusions between a doctor and a patient on treatment becomes clear.

While a doctor is typically presumed to give an objective opinion, how objective can it truly be? Although medicine, for the most part, ignores the reality of its practitioners' implicit value judgements, a doctor must invoke some value structure in order to give advice to a patient. Feminist ethics attempts to make the values used in these "objective" assessments explicit. Doctors need to realize what values they bring to the situation as well as realize how the patient's values may diverge. A

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[8] For example: Susan Sherwin, p. 47, 92.

difference in opinion on treatment may not reflect a patient's lack of faith in a doctor's ability, but merely that other values are in play. Feminists place an emphasis on the context of the situation and how the "web" of a woman's life can not be negated. The relevance and importance of the value assignations given to different parts of a woman's life should affect both the medical and lay risk assessment of breast cancer. Feminists show that these values judgements do have a role to play in decision-making, even if they do not accord with the ones the medical system promotes.

An additional point needs to be made about the importance of consideration and use of different value systems as they relate to (medical) research. This thesis has supported the claim that research is a political and social activity which is not immune to questioning. If science were truly objective and no value judgements were involved in the research process, from choice of topics to methods to evaluation, then we could have no dispute about research. This has not been established though as one only need recall the values I identified as driving the research focus in breast cancer and the risk debate which is formed from these values. Breast cancer advocates must have some ground for pressuring the medical establishment and government for more research funding and for needing to have a role in where this money is directed. Sherwin provides this ground by stating that,

> ...it is important that we recognize that medical research is a political activity; as such, it should be responsive to the principles of participatory democracy...Representatives

> of different interest groups should have input into the process of setting goals and guidelines for research.[9]

Now that the feminist perspective on the medical system and research has been combined with the role of values in risk assessment (pointing to the need for democratic decision-making and required input from all involved parties), the construction of the alternative risk picture can begin.

I believe it is fair to separate the five examples into two, more or less, distinct categories. The first three examples of mammography, prophylactic mastectomy, and tamoxifen/the role of estrogen, for the most part, deal with risk evaluation. Women are in a reactionary position with respect to these offered solutions for altering their risk status. Questioning of these procedures begins mainly with the last step in risk assessment, risk evaluation. The need for improved communication and consideration of the values of the involved women is present for each of the first three examples and shows how one must demand a reconsideration of the topics chosen for risk assessment. Unless one starts to question these technological and pharmacological solutions from the outset, rather than simply focusing in on how women may evaluate these procedures differently or that they may be affected negatively to a greater degree than previously assumed, one continues in many ways to still operate within and accept the narrow risk picture. The alternative risk picture I have been trying to elucidate attempts to address this fact by pushing beyond the current defined "limits"

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[9] Susan Sherwin, p. 174.

for the management of breast cancer risk.

In mammography, it is essential that women be provided with as much information as we currently have on its benefits and risks. This implies demanding better coverage by the media of medical research and procedures (possibly correcting the focus on younger women) as well as pressuring the involved (medical) institutions to adequately convey why there is a discrepancy in their recommendations about mammography. This will most likely draw out the different ranking and use of values by these institutions to make these decisions. In my opinion, awareness of these value judgements could only add to an individual woman's risk evaluation on whether or not to get a mammogram.

Women also need to demand more research into alternative imaging methods for screening which are not as painful, have greater sensitivity and accuracy, and do not have the risk of radiation. Many new methods are currently being researched, but as yet, mammography seems to be the best screening method available. This is where pushing to expand the choice of topics for risk assessment comes in. For example, rather than focusing only on expanding the screening choices for women (which I believe is still needed), one could make the move to addressing the question of prevention of breast cancer.

I believe the call for prophylactic mastectomy revolves around the anxiety, created by various means, about one being at risk for developing breast cancer. The dominant values of technological intervention need to be counteracted by the values of

low-tech, holistic approaches. The need for "correct" communication and understanding of risk is essential if women are to avoid being manipulated physically by the medical establishment. "Correct" communication is here understood to mean that the gaps in the scientific research and medical knowledge of breast cancer would be made known to women privately and publicly (with hopefully fewer contradictions and mistakes), an emphasis on the lack of information about the appropriateness of prophylactic mastectomy would be given, and the need for follow-up despite this surgery made completely clear. I believe that with the proper information, women will be less anxious about the risk of developing breast cancer and that the requests for such drastic means of altering that perceived risk will subsequently decrease, giving women more control over their bodies. As well, by putting pressure on the medical system to justify and explain this procedure, perhaps it would itself undertake a re-evaluation of the risk assessment used to be able to offer prophylactic mastectomies as a "solution" to those women at high risk of developing breast cancer.

From the point of view of risk evaluation, I have shown how complicated this process can become for the individual woman in the section on tamoxifen, HRT, the "Pill", and the role of estrogen in breast cancer. It seems that there are unwanted risks no matter which decision is made by the woman. As the medical establishment has had a large role in specifying what is "normal" for women, this reality becomes even more problematic. When the values of technological intervention and individual causation are added to this control of the definition of what is normal, the degree to

which the female body may be manipulated becomes very real. The dominance of medical values has effectively kept the values of women out of the risk assessment process at all stages.

> ...physicians have gone on to expand their interest in treating women, seeing all aspects and stages of women's normal reproductive lives as material for medical treatment and claiming authority over more and more of women's ordinary experience. In appropriating the authority to define what is normal and healthy for women, they ensured women's continuing dependence upon them.[10]

This is where feminist theory, in its questioning of medical authority, begins to really take hold in this discussion. It shows how the values I have identified as dominating the risk assessment in breast cancer are the ones espoused by the medical establishment. These values are then reinforced by the lay public, which generally accepts medical judgements as an "unqualified good". It has only been in the last part of this century that society has begun to question the role of medicine, part of this being the result of the women's movement, and it has been only in the last twenty years or so that women have started to question the management of breast cancer and its risk. Women need to be the central figure in breast cancer as they are its victims and it is only fitting that their values, not the medical system's, be the dominant force in this disease's risk assessment. Women should not be restricted to an evaluative reactionary position, as is mainly the case in these three areas of breast cancer.

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[10] Susan Sherwin, p. 150-151.

The last two examples, the research routes and prevention, fall into a different category because they are most useful for illuminating the values which can enter into risk assessment from its beginning. Both of these examples can be categorized as questioning the choice of topics for risk assessment; for example, they lead to the identification and criticism of the "constructed research focus" on the role of estrogen in breast cancer. It is these two areas of breast cancer which more clearly show how the involvement of women in the decision-making process can open up avenues for risk assessment (because values, other than the medical system's, are being used).

As I indicated in Section 2.4 on the research routes, use of different values for determining the research focus, results in the difference between researching hormonal manipulation and researching environmental estrogen-mimicking chemicals and carcinogens. One route follows along from the value of technology and the related medicalization of risk, while the other wants to focus on the identification and elimination of the causes of breast cancer. It is my impression that breast cancer advocates do not want the research into the female body to stop, but what they do want is for this research to be balanced by a focus on and interest in the wider socio-environmental factors. These calls for an expanded focus on risk assessment in breast cancer are justifiable, as I have shown previously in both the sections on research routes and prevention (see Sections 2.4 and 2.5). There is both theoretical (eg. that chronic diseases are more closely associated with social and environmental factors) and empirical (eg. the rates of breast cancer around the world) evidence to support this

expansion of focus.

In conclusion, I realize the alternative risk picture I am expounding here is one which will require a much broader social committment to health than is commonly accepted, especially by the medical establishment.

> [Doctor's] domination over the definition of illness and the practice of medicine contributes to the ever growing trend of medicalization and when this trend is combined with a mentality of individualism, it produces a medical care system that resists social responsibility.[11]

But I do believe that the time has come for breast cancer risk assessment to stop being unilateral in favour of the dominant values of the medical system. As I have shown, the risk debates in breast cancer point to different value structures which, in my opinion, have a legitimate basis for inclusion. If research, and the medical establishment by extension, is the political and social activity it has been shown to be, this means that democratic decision-making needs to be paramount. If women are allowed a genuine and central voice in breast cancer risk assessment, the types of research, diagnosis, and treatment which are ultimately offered will most likely change drastically. In many ways, the entering into a true risk debate about breast cancer can challenge us to regard medicine and our society in a very different way. Perhaps not all of the answers will be found and mistakes will be made, but at least all of the involved parties will have the chance for their values to be acknowledged and have the chance to participate fully in the risk assessment for breast cancer.

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[11] Sue Fisher, p. 134.

APPENDIX A: RISK FACTORS FOR BREAST CANCER[1]

This appendix provides a brief outline of the different risk factors which are currently known for breast cancer:

A commonly quoted statistic is that 1 in 8 or 9 women will develop breast cancer during her lifetime. This fact is frequently misinterpreted to mean that this probability of 1 in 8 is uniform over the course of a woman's life. This is not the case though, as this statistic is a representation of the total lifetime odds facing the longest-lived women we can reasonably imagine - those of age 95[2]. The chances of developing breast cancer by age are as follows[3]:

By age 25: 1 in 19 608
By age 30: 1 in 2 525
By age 35: 1 in 622
By age 40: 1 in 217
By age 45: 1 in 93
By age 50: 1 in 50
By age 55: 1 in 33
By age 60: 1 in 24
By age 65: 1 in 17

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[1] I am typically going to refer to breast cancer as a woman's disease. This is not to ignore the fact that men also get breast cancer, but as only one in every hundred cases of breast cancer is a man, I feel it is more appropriate to address the female perspective of this disease.

[2] Self Magazine, "What "One in Eight" Actually Means", *Breast Cancer Handbook '94*, (United States: Self Magazine, Oct. 1994).

[3] National Cancer Institute, *Lifetime Probability of Breast Cancer in American Women*, (United States: NCI; CancerFacts, August 1993).

By age 70: 1 in 14
By age 75: 1 in 11
By age 80: 1 in 10
By age 85: 1 in 9
Ever: 1 in 8

There are two important things to note here; one, these are population-based averages of breast cancer incidence, a woman's individual risk may be higher or lower; and, two, by age eighty more than half of all women have already died - overwhelmingly of other causes[4]. Nevertheless, age is the single most important factor in determining a woman's risk of getting breast cancer.

Other risk factors for developing breast cancer are as follows[5]:

1) family history - if a first degree relative (mother, sister) has breast cancer especially at a young age, one's risk increases by two to five times compared to those without a family history.

It has been estimated that genetic breast cancers, eg. BRCA1, form a small part of all breast cancer cases (<5%) and if one has the gene, the chance of getting breast cancer does not automatically become one-hundred, it only increases the risk as indicated above.

2) cancer history - a woman who has had cancer in one breast, endometrial cancer, or

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[4] *Self Magazine.*

[5] Three sources were combined to develop the following list of risk factors: *Self Magazine*; Curtis Mettlin, "Breast Cancer Risk Factors", *Cancer Supplement* 69(7), (April 1, 1992); I. Craig Henderson, "Risk Factors for Breast Cancer Development", *American Cancer Society*, (United States: Professional Education Publication, March 15, 1993).

ovarian cancer has an increased risk.

3) reproductive history - the following four factors have all been shown to have an effect on risk; the first three all increase a woman's risk.

i) age at menarche: young age (before age twelve)
ii) age at menopause: after age 55 (compared to age 45)
iii) pregnancy: never having a child or delaying childbirth to after age 30 (compared to before 20)
iv) lactation: possible protective effect on premenopausal breast cancer

It is believed that the longer duration of cyclic ovarian activity is associated with greater risk. The effects of pregnancy and lactation cause a woman's breasts to completely mature and may permanently affect her endocrine system which may reduce susceptibility for developing breast cancer. These factors are what have stimulated research/been responsible for the interest in estrogen and its relation to breast cancer.

4) exogenous hormones -

i) postmenopausal estrogen replacement: possible connection to an increase in the chance of getting breast cancer, typically is contrasted to the beneficial effects on osteoporosis and heart disease
ii) oral contraceptives: prolonged usage from an early age (<25 without pregnancy) may put one at a slightly increased risk of developing breast cancer

Daily alcohol consumption, excess fat in one's diet, and exposure to carcinogens, radiation, in the environment are other potential risk factors for breast cancer which are currently being studied. To date, many of the results about the amount of risk or nature of the relationship between these factors and breast cancer is contradictory or unknown.

APPENDIX B: DEFINITIONS OF RISK

This appendix attempts to build an understanding of the different uses of the term "risk". This understanding may help to supplement the discussion of risk discourse found in this thesis.

The technical use of the word risk comes closest to reflecting its original connotation. This is risk as being neutral; a term referring to the probability or mathematical likelihood of an event occurring[1]. Risk, within the medical and social setting, becomes a term signifying danger. This danger can be viewed as the result of two different causes[2]. The first of these is risk as the health danger posed to populations by environmental hazards. This threat is external, is one which the individual has little or no control over, and ends in anger or frustration which is commonly expressed at the government or "big business". The second is risk as a consequence of the "lifestyle" choices made by individuals. The focus here is on self-control and health programs which try to promote change. The potential for moral judgements in this second perspective is obvious and has been dealt with in this thesis (for example, see Section 2.5). Additionally, a third form of risk which Lupton does

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[1] Deborah Lupton, "Risk as Moral Danger: The Social and Political Functions of Risk Discourse in Public Health", *International Journal of Health Services* 23(3), (1993), p. 425.

[2] *Ibid.*, p. 426-427.

not discuss is the risk associated with medical intervention. This is the "risk talk" people are probably most familiar with, i.e. the risk of having heart surgery vs. taking a certain medication. My focus in this thesis is not so much on these "actual" risks (eg. risk of chemotherapy vs. radiation treatment for second stage breast cancer), but on how risk discourse takes place.

The risk of developing a disease, such as breast cancer, is commonly expressed through the use of risk factors. Spratt, Greenburg, et al., point to the different uses of the phrase "risk factor" and state that it can be used in the following ways:

1. An attribute or exposure that is associated with an increased probability of a specified outcome, such as the occurrence of a disease, not necessarily causally related (risk marker)

2. An attribute or exposure that increases the probability of occurrence of disease or other specified outcome (a risk determinant)

3. A determinant that can be modified by intervention, thereby reducing the probability of occurrence or disease or other specified outcomes. A determinant may be considered as a modifiable risk factor.[3]

To avoid confusion, it is necessary for any discussion of risk to clearly state what definition is being used.

How do the risk factors I have laid out in Appendix A fit into these definitions? Obviously, all of the risk factors are risk markers in the sense that they are all associated with a change in the probability of a person developing breast

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[3] John S. Spratt, Richard A. Greenburg, et al., "Breast Cancer Risk: A Review of Definitions and Assessments of Risk", *Journal of Surgical Oncology* 41, (1989), p. 42.

cancer. It also seems to me that many of these risk factors are believed to have a causal role in breast cancer. Although there does seem to be some causal relation between age, the number of ovulations etc. and the chance of developing breast cancer, this relationship has not yet been fully worked out. Thus, I am not comfortable with denoting these factors as determinants; nor are researchers doing this as they are still trying to work out how breast cancer is actually caused. Secondly, most scientists readily admit that there is much which needs to be learned about the causes of breast cancer. Given the fact that these current risk factors only account for approximately one-third of all cases of breast cancer (see Chp. 2, footnote 13), we do not even have all of the possible risk markers identified. Later in this thesis (see discussion of prevention in Chp.2, Chp. 3), the third definition of risk (referring to the modifiable risk factor) becomes important as it plays a role in the social aspect of risk and in discussions of the prevention of breast cancer. While we do not know the causal mechanism leading to breast cancer, many people believe that it is important to act on the information which we do have, including the suspected causal mechanisms, and therefore that we should try to change those risk factors which are typically correlated with breast cancer and may play a role in its development.

It is also necessary to define the "type" of risk we are dealing with when talking about breast cancer. Relative risk and attributable risk are the two possible types of risk which we can use. Relative risk is the ratio of the incidence density on one set of circumstances over the incidence density of another set of circumstances,

whereas, attributable risk is the proportion of the disease in the total population that can be attributed to exposure to the suspected causal agent[4]. Since the cause(s) of breast cancer is unknown, relative risk is the type of risk we should be using in our risk discourse.

There are four things which make the determination of individual breast cancer risk difficult:

a) there exists much uncertainty within epidemiology [the field where technical risk is usually calculated for human diseases] concerning the significance of the identified risk factors

b) ...uncertainty within both epidemiology and other biomedical sciences concerning the relationships between identified risk factors and the mechanisms of disease

c) it is impossible to accurately translate population risk to individual risk

d) it is impossible [to] accurately know all the contextual factors and how they interact to determine risk for unique individuals[5]

I believe much of this uncertainty is typically not communicated within risk discourse and remains either implicit (among those who are knowledgable of these factors) or hidden (among those who are not familiar with the interpretation of statistics). This belief helps shape the alternative conception of risk I attempt to build in this thesis.

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[4] *Ibid.*, p. 43.

[5] Sandra Gifford, p. 231.

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