FOUR DISCOURSES ABOUT BREAST CANCER: A BROADER VIEW

by

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ABSTRACT

Breast cancer has become a modern day epidemic. Over 19,000 women will be diagnosed with breast cancer this year in Canada, and over 5,000 will die. Health care providers and the public need to find better ways to understand the complexity of this disease. Universal explanations for such phenomena are no longer acceptable. Multiple “other” views must be recognized. To seek out truth it is necessary to make the invisible, visible. This thesis is an attempt to reveal competing discourses that construct breast cancer.

Models help us see the world in different ways. The four world-view model is a tool that recognizes four different ways of thinking about phenomena. These four viewpoints (functionalism, humanism, radical functionalism and radical humanism) encompass ontological differences (subjectivity versus objectivity) and extant power relations differences (challenge versus reinforcement). Functionalists view reality objectively, and assume that society is stable and status quo is maintained. Humanists also view society as stable and status quo as acceptable, but reality is subjectively constructed. Both radical functionalists and radical humanists believe that there are deep-seated conflicts between the elite and the underclasses and change is needed. Radical functionalists view the world objectively and believe that the underclasses are controlled via information and material constraints, while radical humanists view the world from a subjective viewpoint and believe superstructures disempower the underclasses.

In this study breast cancer literature was reviewed to find examples that illustrate the four perspectives of the four world-view model. Each article, book, and website was “questioned” using an interview guide based on the four world-view model. Samples were selected to reflect several issues that were relevant to each perspective. The goal of this study was to use the four world-model as a framework for creating a broad and complex description of breast cancer. The intent was never to create an exhaustive description of breast cancer. By using the four world-view model to describe various perspectives of breast cancer, a broader discourse has been uncovered. Multiple viewpoints have been recognized.

For many years breast cancer has been defined from a functionalist perspective. Biology defined breast cancer. Research identified various aspects of breast cancer; how cells multiply and grow, what treatments best halt the spread of cancer, and what treatments do not affect the growth and recurrence of breast cancer.

The humanist perspective explores the personal stories of breast cancer. Breast cancer has been described in many ways, sometimes as enemy, challenge and opportunity for transformation. Each way of experiencing breast cancer needs to be recognized and honored for its truthfulness and legitimacy.

According to the radical functionalist perspective, large corporations and physicians, the elitist members of society, have been responsible for determining how breast cancer is researched and treated. These powerful groups controlled material resources and
information, ensuring their needs for prestige and profits are met, with little regard for the needs of women with the disease. Women’s lack of societal power has had a significant effect on the treatment patterns for this disease. Many women have undergone disfiguring surgical procedures and drug research trials without their informed consent. Often decisions have been made regarding breast cancer treatment to continue the power and profitability of physicians and corporations, not to best meet the needs of women with breast cancer.

The radical humanist perspective also illustrates how social structures and privileged elites have influenced breast cancer. Society has blamed and shamed women into silence. Women have been convinced that it is necessary to hide breast cancer behind prosthesis and augmentation surgery to ensure their desirability and value. By staying silent about breast cancer, women have fulfilled their role as mother and partner, putting their needs behind the needs of their family. Breast cancer continues to be a taboo subject; this has created a silence. This silence has ensured that breast cancer is viewed as a personal tragedy, only spoken about in family circles, instead of as a preventable health care crisis.

By looking at breast cancer through the four lenses of the world-view model, a broader discourse of breast cancer unfolds. Breast cancer is no longer just a biological issue that is treated with surgery, radiation and chemotherapy. It is a personal tragedy for the women with the disease, changing their lives forever. It is also a social phenomenon where society has influenced how it is treated, researched and experienced by the women with it. If truth is sought, which can be defined as absence of concealment, it is necessary to make the invisible visible and not to reject particular ways of knowing. By using the four world-view model to describe the different perspectives of breast cancer new and diverse ways of seeing breast cancer are uncovered.

This broader description of breast cancer can be used to inform decisions made by healthcare teams as well as guide educational planning for health care professionals and the public. The four world-view model creates space for alternative viewpoints, which is can lead to a more comprehensive and complex understanding of disease. Healthcare teams can incorporate this broader understanding into their planning, potentially developing creative programs that address a variety of needs for people with disease. The four world-view model can also be used as a guide for educational planning for health care professionals, students and the public. The broad definition of disease that is created through the use of the four world-view model can be represented at conferences, in classrooms and in public information documents. This broader description provides space for the personal experience of disease as well as how society has an impact on how disease is experienced and treated.
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DEDICATION

To Chuck
CHAPTER ONE

WORLD VIEWS ON BREAST CANCER

Recently I was the leader of a group of health care providers trying to develop a proposal for a breast cancer program for the community. To be inclusive, a variety of people were invited to meet. These meetings went nowhere. After three months we were still disagreeing on the fundamental philosophy of the program. The two physicians wanted to develop a clinic that would diagnose and recommend treatment for women with breast cancer. The fitness programmer from the city wanted to provide an exercise program for women to increase their activity. The dietitian wanted to work with the school board to remove the profit making “junk food” machines from high schools. Staff from the Health Department wanted to work with women with breast cancer to develop a volunteer run education program for people with cancer. Each idea would need funding.

Now when I look back at this team, I realize members of this group all viewed breast cancer differently. We never spent time addressing the differences. Each person just kept trying to convince others that their project was the right way to spend the money. (This scenario has been slightly modified to better illustrate the underlying issues, but is based on a true situation – June 2000).

Breast cancer has become a modern day epidemic. It can strike women as young as 30 years old, and is commonly seen in women in their 70’s and 80’s. One in eight women who have reached the age of 80 will be diagnosed with breast cancer (Batt, 1994). The incidence of breast cancer continues to rise, with a 1– 2 % per year increase since World War II (Canadian Cancer Statistics, 2000). Even though there has been extensive research on breast cancer, for many cases the cause of breast cancer is still unknown. About 50% of women with breast cancer have high-risk indicators present: early menarche, older ages at birth of first child or childlessness, late menopause, and a sister or mother diagnosed with breast cancer (Love, 2000). But for more than 50% of breast cancer victims there is no answer to the pervasive question “why me?”

Recent research has identified two genes linked with breast cancer. This has often been touted as a “break through in breast cancer research”, but only 2.5 – 5% of all breast cancers can be linked to these genes (Rosser, 2000). For almost 50% of women with breast cancer, there is no answer to ‘why’ and no suggestions about how to protect their daughters from this potentially fatal disease. Preliminary research uncovered potential links between hazardous waste sites, pesticides, polyvinyl chloride, synthetic hormones, radiation and breast cancer, but funding for this type of research has been minimal, so conclusive studies have not yet been forthcoming (Steingraber, 2000).

In the last 30 years there has been major changes in the treatment of breast cancer. In the past, aggressive, extensive, mutilating surgery was the norm. Now minimal surgery, followed by chemotherapy or radiation treatment has become the new standard of care. Once a ‘suspicious’ breast lump is found, either by a computer-generated mammography
scan, or by physical examination, testing begins to identify properties of the lump. A variety of procedures determine the type of cells present in the tumor, the size of the tumor, and the possible invasion of cancer cells into other tissues. After the specific properties of the cancer are determined, a treatment plan is developed. Depending on the type of cancer cells and invasiveness of the tumor, a woman has several choices of treatments. The most common is minimal surgery followed by radiation therapy and/or chemotherapy. Women whose breast cancer is identified and treated early have a 95% chance of surviving five years, while women with aggressive cancer have approximately a 60% chance of their breast cancer recurring in less than 10 years (Illivotto, Gelmon and Kuusk, 1995).

Women have begun to speak out about their cancer experience. Many famous women have told their stories of their “battle with cancer”. For some women, breast cancer has been an opportunity to transform their life (Coward, 1991). It provided them with new purpose and perspective. But, for many women, cancer is synonymous with fear. Fear of suffering, death, recurrence, loss of ‘femininity’, and loss of a normal life (Utley, 1999).

Even though famous women’s stories line the shelves in libraries and bookstores, non-famous women often keep their breast cancer hidden. Societal expectations dictate that women with breast cancer cover up their disease with prostheses and breast reconstruction surgery. These modifications to their bodies ensure that they continue to have a symmetrical, feminine, desirable shape, ensuring their continued value to society (Kasper, 1988). Many women often feel pressure from others to keep cancer stories to themselves, admit to no one just how bad their struggle against it was (Rosenbaum and Roos, 2000). Breast cancer continues to be hidden behind prostheses, surgery and silence, maintaining it as a woman’s private struggle instead of the health epidemic that it is.

Society has had a powerful role in dictating how breast cancer is treated. Physicians and large corporations have determined what research will be done and treatments provided (Batt, 1994). Women with breast cancer have had little or no voice in the discussions about what should be researched and treatments covered by universal health care. Until recently women with breast cancer did not have access to information about breast cancer research and treatment protocols and therefore had no input into decisions about treatment. Until the 1980’s physicians routinely provided women with aggressive debilitating treatments which had no better outcomes than less invasive options (Batt, 1994). Many times women’s best interests fell behind the interests of physicians, pharmaceutical companies and large organizations (Breast Cancer Action, 2000).

Over 19,000 women will be diagnosed with breast cancer this year in Canada, and over 5,000 will die (National Cancer Institute of Canada, 2000). These women will struggle to make sense of their disease; why did they get it, will they survive, will they be less of a woman, and will their daughters get it? As these women wrestle with questions, health care providers and the public need to find better ways to understand the complexity of this disease. In today’s world people reject universal explanations for phenomena.
Women and other minorities are demanding that their unique views of reality be recognized as legitimate. Differences between the old dominant view of reality and the multiple “other” views are becoming more obvious in health care. To seek out truth it is necessary to make the invisible visible and not to reject different ways of viewing phenomena. This thesis is an attempt to broaden the discourse that constructs conceptions of breast cancer.

**Four World-View Model**

There are tools that assist us in seeing the world in different ways. Burrell and Morgan (1977) created a model that maps different ways of looking at phenomena. They proposed that this model, the four world-view model depicts all the different ways of viewing phenomena. Burrell and Morgan used this model to illustrate different sociological theories. Paulston (1996) and Paulston and Liebman (1994) also used this model to graphically represent educational theories and their relationships to each other. Boshier used the Paulston’s adaptation of the four world-view model to describe international AIDS education programs (1990) as well as fishing vessel accidents and their prevention (1999). Nicholson-Goodman (1996) used a variation of this model to map environmental education, while Mausolff (1996) used it to explain the differences in the participation of rural development projects. Each of these studies used the four world-view model to broaden the discourse of the phenomena. Space was provided for multiple perspectives on the phenomenon, thus creating a more comprehensive and complex understanding of it.

The basic tenet of the four world-view model is that the different ways people view the world are based on their assumptions about the world (Burrell and Morgan, 1977). Two sets of assumptions define these perspectives, the subjective-objective dimension and the reinforce-challenge dimension.

The subjective-objective dimension relates to how people think about ontology. In the objective dimension, knowledge is considered ‘external’ to the individual. Knowledge is viewed as hard, real and capable of being transmitted in a tangible form. Researchers who work in this dimension search for universal laws that explain and govern phenomena.

The subjective dimension recognizes that human understanding of phenomena is based on our experience of the world. Reality is a product of one's mind. In the subjective dimension humans create their own understanding of phenomena. People determine reality. When researchers search for understanding in the subjective dimension, they investigate how individuals create, modify and interpret phenomenon.

The reinforce-challenge dimension explains how society reinforces or challenges extant power relations. The reinforcing dimension supports the belief that every society is relatively stable, well integrated and every element in society has a function. The
challenge dimension operates from a belief that social change and conflict is ubiquitous and every element contributes to disintegration and change.

In Burrell and Morgan's model, these two sets of assumptions were depicted on a four-fold table. The horizontal axis is comprised of the subjective and objective viewpoints, labeled ontology. Challenge and reinforce are situated at either end of the vertical axis, labeled extant power relations (Figure 1). When these assumptions are lined up, four perspectives are created: functionalism, interpretivism, radical structuralism, and radical humanism. Each perspective views phenomena in distinctly different ways. Burrell and Morgan proposed that all viewpoints fit into one of these four perspectives.

**Figure 1.** Four world-view model by Burrell and Morgan.

Functionalism views reality as objective, and society's role as reinforcing power relations. Interpretivism also views society's role as reinforcing extant power relations, but it views reality from a subjective viewpoint. Radical humanism and radical structuralism both view society's role as challenging extant power relations. Radical humanism views reality from a subjective viewpoint while radical structuralism views reality from an objective viewpoint.
How Breast Cancer Would Appear Utilizing the Four World Views

In this study, literature on breast cancer in women is viewed from the following four perspectives. Each perspective depicts breast cancer differently.

Functionalism

Most people think about breast cancer from a functionalist perspective. Breast cancer is seen as a group of abnormal cells that can be destroyed by surgery, radiation and chemotherapy. Research is done to uncover ‘universal laws’ that govern cancer cell growth and destruction. Work is done to identify the most effective ways of eliminating cancer. This is the dominant perspective in health care. The focus for breast cancer is determining treatment plans based on large randomized controlled studies.

Interpretivism

The interpretivist perspective foregrounds subjectivity. In this perspective, society is stable and integrated, and extant power relations reinforced. Because subjective reality is based on experiences, outsiders can only comprehend the phenomenon of breast cancer through the words of women with the disease. Women with breast cancer view it as both a positive and negative experience. Three of the ways breast cancer has been described by women with the disease are as enemy, challenge and transformation.

Radical Structuralism

Radical structuralism views reality as objective. Structural conflict is endemic. Breast cancer activists function from this perspective. Physicians, corporations, and health care organizations control breast cancer research and treatment in order to enhance their socio-political positions, not the needs of women with the disease. Through the dissemination of information and by changing government control, breast cancer activists have worked at modifying the balance of power and the way cancer care is provided.

Radical Humanism

The radical humanist perspective views reality subjectively and wants to challenge power relations. Radical humanists believe superstructures (government, schools, corporations, and media) control people. These superstructures must be overthrown so people can live genuinely. This perspective recognizes how social forces affect ways people think about breast cancer. Radical humanists believe women with breast cancer experience a contradiction between how society expects them to react and their own experience of the disease. For example, society expects women who have had a mastectomy to feel ‘less of a woman’ since they have lost a breast; they are expected to hide their imperfect image behind prosthesis. Many women find that losing a breast is not a significant issue in their
battle with cancer but are pressured to react to this so society’s expectations are confirmed.

**Purpose of the Study**

*My role as a team facilitator has exposed me to a new trend in today’s health care organizations - small, diverse work teams. These teams are made up of health care professionals and members of the public. Their purpose is to develop innovative ways to address health care issues. Often these groups have very little success in creating “innovative” solutions. Frequently the “solution” the team endorses has been proposed, and lobbied for, by the most powerful members of the group. If this type of work is to continue, and there does not appear to be any waning of interest in this strategy, more effective ways of working in these situations are needed.*

*A fundamental problem in these groups is the lack of recognition of perspective differences represented by the group members. Differences are glossed over, with little frank discussion about the impact of diverse viewpoints on the functioning of the team. If team members are to work well together recognition of the variety of perspectives on the issues needs to occur. After these different perspectives are recognized, discussion can define the issue that will be addressed by the group. After these steps the group can begin to discuss possible strategies.*

*The four world-view model is a graphical way of representing different perspectives. It helps people recognize perspectives beyond their own. It illustrates similarities and differences between perspectives, which can lead to new questions, viewpoints and solutions. It is a tool to broaden the understanding of breast cancer.*

The purpose of this study was to use the four world-view model to broaden the discourse that constructs breast cancer. This model provides space for multiple perspectives, therefore creating a more comprehensive and complex understanding.

The four world-view model could have been used by the multi-disciplinary health care planning team to illustrate the variety of viewpoints regarding breast cancer. This graphical representation of the different perspectives of breast cancer could demonstrate the similarities and differences between the viewpoints, providing space for all perspectives, thus preventing the silencing of some. Once the team achieved a more comprehensive understanding of breast cancer, discussion could then occur regarding how to plan services. Different perspectives could be used to critique potential plans and planners could recognize whose needs were being met or ignored.

The four world-view model could also provide a framework for educating health care professionals, students and the public. By using the model as a framework for education planning, a variety of perspectives can be given space. This model could be used for planning continuing education conferences, lectures for students in health care programs and for educational pamphlets and programs for the public. By ensuring a variety of
perspectives are represented in the educational program and materials, learners would be exposed to several viewpoints. This would prevent the domination of the functionalist view of disease. Using the four perspectives of the four world-view model could pursue a more comprehensive and complex understanding of disease.

Overview of the Thesis

Chapter 2 discusses the four-world view model by Burrell and Morgan (1979), and modifications to the model by Paulston (1996). Chapter 3 addresses the methodology of the study. Examples from each perspective were identified by querying journal articles, books and websites using pre-determined criteria created from the descriptions of the four world-view model.

Chapters 4, 5, 6, and 7 discuss how breast cancer is viewed from each perspective. Each chapter is written in the voice of one who lives in the perspective. Breast cancer is spoken about differently in each chapter in an attempt to depict significant issues from each perspective. These chapters are not meant to be a comprehensive summary of all of the information available from each perspective, but rather a sample of issues identified by each of the perspectives.

Chapter 4 discusses breast cancer from the functionalist perspective. It focuses on understanding the properties of breast cancer and the three most common treatments, surgery, radiation and chemotherapy. In this perspective, the effective treatment of breast cancer is the key issue.

Chapter 5 discusses breast cancer from the humanist (interpretivist) perspective. It focuses on understanding the personal impact of breast cancer via the words of women. This chapter relies heavily on these women’s words, taken from extensive interviews in the humanist literature. By using quotes from women with breast cancer, space is provided to describe cancer as “enemy”, “challenge” and “transformation”.

Chapter 6 is the radical functionalist (radical structuralist) viewpoint. From this viewpoint, breast cancer research and treatment is controlled by powerful organizations. Radical functionalists recommend changes to breast cancer treatment and research so the needs of women are put ahead of large organizations. Access to comprehensive information, safer less invasive treatments and research into prevention is discussed in this chapter.

Chapter 7 views breast cancer from the radical humanist perspective. This chapter explores how society dictates how women experience breast cancer. Radical humanists believe there is a profound contradiction between the public’s expectations of how women with breast cancer should experience the disease and these women’s experience. Three radical humanist themes are explored in this chapter: how appearance defines a
woman, how women's needs are secondary to others and how breast cancer is a taboo subject for most women.

Figure 2 graphically illustrates the different perspectives of breast cancer discussed in chapters 4, 5, 6, and 7. This figure uses Paulston's adapted perspective labels and uses the structure of Burrell and Morgan's model. Breast cancer issues for each of the four perspectives are listed on the figure in the appropriate areas to help the reader identify and compare similarities and differences in the four world-views.

![Figure 2 Four World-Views of Breast Cancer]

Chapter 8 summarizes how breast cancer is viewed from the four perspectives. The utility of the four world-view model to describe health care phenomena is discussed as well as the implications for health care planning and education. The strengths and limitations of the study are reviewed.
CHAPTER TWO

FOUR WORLD VIEWS

Theory of World Views

There are four different ways of thinking about social phenomena. The traditional scientific perspective is the most dominant. To understand the four world-views assumptions that frame the way people think about the world must be recognized.

In Burrell and Morgan's (1979) model, assumptions fall into two major categories: subjective versus objective and conflict versus order. The subjective - objective dimension relates to how humans perceive reality. Subjectivists assume knowledge is unique and personal, and a product of one’s mind. Humans are autonomous and free willed and they create their own universe. Subjective reality can only be understood from the point of view of individuals directly involved, therefore the traditional outside observer cannot understand the phenomena. The principal concern to be investigated is how individuals create, modify and interpret the world in which they find themselves. Phenomena are investigated differently than the way a researcher who has an objective viewpoint would do it. Because the subjective world can only be understood by obtaining first hand knowledge of the phenomena under investigation, researchers must get close to their subject - get inside the situation and involve themselves in the everyday flow of life through the use of diaries, biographies and journalistic records. This type of research lets the subject’s understanding of the phenomena unfold during the investigation.

Objectivists assume knowledge is objective, and reality external to the individual. Humans and their activities are determined by the situation and environment. The nature of knowledge is hard, real, and capable of being transmitted in a tangible form. The goal for this type of research is to identify universal laws that explain and govern observable reality. Research follows systematic protocols and techniques. Hypotheses are created and tested using standardized scientific tests.

The other dimension, conflict versus order, relates to how the elite members of society struggle to maintain order while the underclasses attempt to create conflict. Burrell and Morgan have named this dichotomy as “reinforcing and challenging extant power relations”. Reinforcing theories seek to understand why society tends to hold together. These theories are concerned with the status quo, social order, voluntary and spontaneous agreement of opinion, social integration, cohesion, solidarity, and identifying and satisfying human needs within the context of the social system. Reinforcing theories are concerned with how societies currently function.

Challenging theories are concerned with how societies “could be”. They focus on deep-seated structural conflict and modes of domination. The goal of challenging theories is to emancipate humans from structures that limit their potential for development.
Challenging theories are concerned with radical change, structural conflict, modes of domination, contradiction in society, emancipation of individuals, and the deprivation of human needs (Burrell and Morgan, 1979).

When these dimensions are presented in a four-fold table, four world-views emerge: functionalism, interpretivism, radical humanism, and radical structuralism. Figure 1 depicts the relationships of these four world-views with subjective views (interpretivism and radical humanism) aligning on the left side of the model, while objective viewpoints (functionalism and radical structuralism) on the right. Order viewpoints (interpretivism and functionalism) are situated on the bottom half of the model, while conflict viewpoints (radical humanism and radical structuralism) are on the top.

**Functionalism**

Functionalism, situated in the bottom right quadrant of the model, claims an objective view of reality and an orderly society. It is the dominant world-view of North Americans. Functionalism attempts to provide explanations for how knowledge is ordered. It seeks rational explanations to rational problems. Knowledge is generated to solve practical problems and issues. Functionalism is based on the natural sciences and evidence is created by researchers observing phenomena and explaining relationships through mathematical, mechanical and biological analogies.

**Interpretivism**

Interpretivism, situated in the bottom left quadrant of the model, supports the view of reality as a subjective experience and society as orderly. The primary concern of interpretivism is to understand the world. Interpretivist theories are constructed from the standpoint of the participant, not the observer. Interpretivists believe the individual creates the world and the outside world is made up of shared assumptions and meanings. The goal of interpretivist research is to understand the fundamental meaning of the world as people experience it.

**Radical Structuralism**

Radical structuralism, situated in the top right quadrant of the model, is committed to emancipation through radical change and sees reality objectively. This perspective views the world as external to the individual, sees humans and their activities determined by situations and environments, and believes knowledge can be discovered through traditional scientific testing. In this perspective the interests of the elite outweigh the needs of the underclasses. The elites dominate the situation through control of information and material resources. The focus of radical structuralism is understanding how society can be changed through intense political or economic conflicts.
Radical Humanism

Radical humanism, situated in the top left quadrant of the model, explores the subjective experience of the individual and is committed to challenging extant power relations. The goal of radical humanism is to overthrow or transcend the limitations of existing social arrangements. Radical Humanists believe ideological superstructures dominate humans’ consciousness. These superstructures (government, schools, and employers) have driven a wedge between what we are and what we could be. These superstructures create alienation and negative consciousness and prevent human fulfillment. Radical humanists look for ways to release constraints that control human behavior. The emphasis of radical humanists is on emancipating humans by ending domination and deprivation through radical change. Radical humanists are also very involved in increasing awareness of human domination by critiquing the status quo and identifying anti-human structures of society. Radical humanists believe change in the social world will occur through a change in the cognition and consciousness of its individual members.

Significance of Mapping World Views

In a post-modern world, people are prone to reject universal explanations for phenomena. Women, First Nation’s people, and other minorities demand that their views of the world be recognized. Differences between the old dominant view of reality and the multiple other views are becoming obvious in every professional field. Recognizing this, Paulston and Liebman (1994) took Burrell and Morgan’s model and used it to graphically describe how educational theories relate to the four world-views. Educational theories were mapped onto the four world-view model in an effort to visually depict relationships among theories. As each theory was mapped it became apparent how these theories related to each other by where they were situated in relation to the four perspectives. This type of map has been defined as social cartography. Beauchamp writes about the utility of social cartography in the introduction to Paulston’s book. Social cartography is seen as "simply a recognition of diverse ideas; and opens space to all views, privileges none, and problematizes all" (Beauchamp, 1996, p.xxii). By mapping ideas the reader is able to identify and compare differences, reveal multiple intersections, and cross boundaries. Mapping can be a powerful strategy to facilitate learning and unlearning, and to allow for transformation (Beauchamp, 1996).

Mapping allows for expression of a variety of ideas, situated so comparisons and contrasts of the different perspectives of the phenomenon become apparent. When looking at these maps, the reader may ask “what can be gained from this exercise? What is the purpose? And why is it necessary to understand others’ points of view?” Beauchamp gives concrete and practical answers to these questions by discussing how schooling and learning benefit from being mapped. He believes that:

when we step beyond our own limited experience and our commonly held assumptions about schools and learning in order to look back at our system in
contrast to another, we see it in a very different light. But a conscious recognition that there are other ways of doing things can serve to open our minds and provoke our imaginations in ways that can result in new experiments or approaches that we may not have otherwise considered (Beauchamp, 1996, p. xiv).

Beauchamp also relates the importance of mapping these ideas visually. "Maps emphasize spatial relations and patterns of difference. Help us 'know' something so we can 'see' differently. Maps can open up space for presenting differences and represent conflicting visions of the future" (1996, p. xvii).

Marton and Booth (1997) defined the most complex level of understanding as being able to simultaneously understand both the parts and the whole of a phenomenon. Learning has occurred when more parts than before are discerned and when more aspects are simultaneously and focally in the awareness. When this occurs, understanding of the phenomenon has changed and become more complex.

Social cartography illustrates different viewpoints. It is a tool to understand phenomena at a more complex level (Paulston, 1996). Paulston writes eloquently about the usefulness of mapping phenomena. He believes that if truth is sought, which is defined as absence of concealment, it is necessary to make the invisible visible and not to reject particular ways of knowing. Maps can demystify ideas and illustrate diverse ways of seeing. They can organize volumes of data into usable information with recognizable patterns and relationships. Social mapping highlights alternative worlds - but it does not build these alternative worlds (Paulston and Liebman, 1994).

**Changes to the Four World-View Model**

Paulston first began to use the Burrell model to map educational theories in 1988. This model provided space for all theories to be represented, so it was possible to visually depict the many ways individuals, groups and organizations view phenomena. Over time Paulston has modified the model, by changing some of the names of the quadrants and eventually reshaping the model. The labels of functionalism and radical humanism have remained, but interpretivism has been changed to humanism, and radical structuralism has been changed to radical functionalism. The model in 1996 is no longer depicted as four rigid quadrants; it has been modified to create two overlapping circles that allow for post-modern fluidity (Figure 3). Also included in this model are arrows that depict the relationships of the theories to the four perspectives. Some theories have several arrows connecting them to different perspectives. The purpose of the arrows is to depict how these theories connect to the world-views. The closer the theory is to the world-view label, the stronger the relationship.

This model has gone through several other modifications in an effort to describe international AIDS education programs (Boshier, 1990), environmental education (Nicholson-Goodman, 1996), participation in rural development programs (Mausolff,
view model provided a tool to broaden the discourse of the phenomena. Space was provided for multiple perspectives, creating a more comprehensive and complex understanding.

Figure 3. Paulston's (1996) adaptation of the four world-view model.

Summary

The four world-view model has been used to map a variety of phenomena. This model categorizes viewpoints by the assumptions that underly them, proposing that all viewpoints relate to the four world-views of functionalism, humanism, radical functionalism and radical humanism. By mapping these theories in relation to what assumptions they ascribe to, similarities and differences between them become apparent. The world-view model is a tool of learning, a way of organizing volumes of data into usable information and recognizable patterns and relationships. Mapping viewpoints onto this model makes the invisible visible and assists people to recognize alternative views, thus reaching a more complex understanding.
CHAPTER THREE

METHODOLOGY

The goal of this study was to use the four world-model as a framework for creating a broad and complex description of the literature on breast cancer. The intent was never to create an exhaustive description of breast cancer. Assumptions in the model were used to create a type of “interview guide” used to query literature, to determine which perspective the document ascribed to. An extensive search was used to find a wide range of literature to cover different perspectives. Not all literature on breast cancer was utilized, samples were selected to reflect issues relevant to each perspective.

Determining the Perspective

Burrell and Morgan (1979) discussed how social theories fit the four perspectives. When they wrote about sorting theories, they did not discuss how they determined where each theory belonged. In Paulston’s (1994) and Paulston and Liebman’s (1996) work, educational theories are mapped onto an adaptation of the four world-views model. The process used for determining where the theories would be positioned on the map was never discussed. Burrell and Morgan (1979) and Paulston and Liebman (1994) did write in detail about the foundations of the model, the objective – subjective and the challenge – reinforce dimensions, and how they lined up to create the four perspectives, functionalism, humanism, radical functionalism and radical humanism.

A type of “interview guide”, (Table 1) was created from the descriptions of the two sets of assumptions defined by Burrell and Morgan (1979) and Paulston and Liebman (1994). On the left side of the table there were four questions about the subjective – objective and challenge – reinforce dimensions. Answers were arrayed under the four perspectives, functionalism, humanism, radical functionalism and radical humanism.

Each book, website, report, article, poem, photojournal report etc. was read twice, once for content and first impressions and then again to determine how it fit the four world-view model. The interview guide was used to query the literature, much like how one would interview a person to determine what perspective they used to view the world.

The first question - “how is reality described?” tries to elicit information about how the author views the world. Is the world seen subjectively, where knowledge is based on experience, humans are autonomous and free willed and where reality is understood in relation to their other experiences? Or does the author see the world objectively, where reality is external to humans, where it can be observed and measured, and where universal laws control phenomena? Also, it is necessary to determine the role society takes in determining reality. The functionalist and humanist perspective does not mention the role of society, while the radical functionalist and radical humanist sees power elites dominating the underclasses.
Table 1
Querying the Literature: Using Concepts from the Four World-View Model

<table>
<thead>
<tr>
<th>Question</th>
<th>Functionalist</th>
<th>Humanist</th>
<th>Radical Functionalist</th>
<th>Radical Humanist</th>
</tr>
</thead>
<tbody>
<tr>
<td>How is reality described?</td>
<td>There is an objective reality that is external to the individual, therefore it can be observed. Universal laws explain it.</td>
<td>Individuals subjectively construct their own reality through perception and cognition.</td>
<td>There is an objective reality that enhances the interests of elites and suppresses the aspirations of the underclasses. This material &quot;reality&quot; is outside the consciousness of human actors (Marx).</td>
<td>Individuals view reality subjectively and carry a false consciousness created by superstructures (government, schools, corporations, and media).</td>
</tr>
<tr>
<td>What techniques are utilized to collect data?</td>
<td>Hypotheses testing through laboratory investigations and clinical trials. The gold standard is the randomized double-blinded studies.</td>
<td>In-depth interviews and dialogue with participants of the phenomena.</td>
<td>Objectivist data gathering such as surveys, analysis of census data. Questions are framed from a critical, radical or Marxian &quot;materialist&quot; perspective.</td>
<td>Participatory, democratic, conscientization processes. Dialogue, popular methodologies such as music, poetry, and drama</td>
</tr>
<tr>
<td>How is society viewed?</td>
<td>Status quo is acceptable. Society can be improved through slow, technical, &quot;objective&quot; incremental changes.</td>
<td>Status quo is acceptable although it is desirable to have greater regard for human subjectivity.</td>
<td>There are deep-seated structural conflicts where elites control information and material resources so as to enhance their socio-political position. Attempts to control &quot;consciousness&quot; are less important than the manipulation of material assets.</td>
<td>Society contains contradictions and conflict but humans can take collective action to change their situation. Changing the social situation is possible through changes in cognition and consciousness of its individual members.</td>
</tr>
<tr>
<td>What is the relationship between the phenomena under study and society?</td>
<td>Society supports the technical and biological viewpoint of breast cancer by funding &quot;objective&quot; research and cancer treatments.</td>
<td>Women's personal experiences with breast cancer are recognized by society. Their experience is not viewed in context of societal pressures.</td>
<td>Drug companies, physicians, and other privileged elites construct the material conditions of breast cancer to enhance their interests. The material conditions of society should be changed via changes in rules and regulations.</td>
<td>The prejudicial and disempowering notions from the power elite create women's personal experience with breast cancer. Women with breast cancer must become conscious of society's role in dictating their experience and work together to change this through conscientization.</td>
</tr>
</tbody>
</table>
poetry? Or are objective techniques used, such as standardized scientific tests, surveys and census data?

The third question—"how is society viewed?"—was used to determine the author's viewpoint on society. Was society seen as reinforcing the current context? Or is society seen as challenging—where structural conflict and domination allows some members of society to succeed while others are prevented from reaching their potential? Usually articles that took on a humanist or functionalist viewpoint would not mention society. Society was viewed as stable, with no need for change. Therefore there was no need to mention it in the literature. In literature with a radical humanist or radical functionalist viewpoint, the role of society was explicitly mentioned, usually forcefully and repeatedly. When reviewing the radical functionalist and radical humanist literature there was no doubt when the author was challenging assumptions. It was openly stated.

The fourth question—"what is the relationship between the phenomena under study and society?"—tries to elicit information about how the author views the impact of society on the phenomena. In the functionalist and humanist perspective, society is seen as supportive of the viewpoint, with some recognition for need for increased awareness of the significance of the personal experience of breast cancer. Society supports the functionalist perspective with significant funding for functionalist research. In the radical humanist and radical functionalist perspectives there is recognition of the need for society to change to create a more equitable society where underclasses needs are better met.

Many articles and books were found to consist of a combination of more than one perspective, as illustrated by the article by Anderson et al (1998) on stress and breast cancer. This study investigated how a stressful situation had a negative impact on women. The negativity of this situation was evidenced by objective data, a decrease in the levels of t-lymphocytes (a component of the immune response) in the circulating blood (Anderson et al., 1998). Even though the study was about a personal response to a situation, the data collection technique was from the functionalist perspective. If this study had been written from a humanist perspective, the data collection would have been consistent with this, such as using in-depth interviews with women who had breast cancer to understand from their viewpoint how breast cancer is a stressful experience. This study was not included in the study due to its mixture of perspectives.

For this study, literature was simply sorted into the four perspectives. Literature that consistently followed one theoretical viewpoint was chosen to illustrate each perspective. If the purpose of this study was to map, rather than sort, breast cancer literature onto the four-world view models, literature that reflected a mixture of perspectives could have been used. Articles and books that represented several perspectives could have been mapped onto the model with connecting arrows from each perspective that informed the work, similar to the way Paulston mapped comparative education theory. But for the purposes of this study only literature that consistently followed one perspective was used.
Finding the Literature

In an effort to find material depicting breast cancer from each of the four perspectives, a wide range of literature was reviewed. Several strategies were used to locate it; contacting various breast cancer care providers, Internet searches, visits to public libraries, and hand searches of journals. There is a plethora of published work on breast cancer. One of the challenges of this study was to not become too absorbed in any one perspective. Each chapter could have easily grown into its own study. Another challenge was to find literature from each perspective. My background in health care made it easy to find examples of functionalist literature. Finding examples for the other three perspectives, humanism, radical humanism and radical functionalism, was much more difficult. Examples from these perspectives were not found in an orderly manner. It was a haphazard journey with each book, website, report and article leading me in another direction. Over time I became familiar with the literature produced by activist groups as well as work by poets and photojournalists. To do this study, I had to become familiar with a wide variety of published works on breast cancer in order to find examples of each perspective. The goal for this study was to describe breast cancer, through the literature, from the functionalist, humanist, radical functionalist and radical humanist perspectives, not to create a comprehensive overview of breast cancer. Due to the sheer volume of information about breast cancer and care, each perspective was limited to three or four issues that were representative samples.

Using the Literature

Chapters Four, Five, Six and Seven respectively describe breast cancer from the Functionalist, Humanist, Radical Functionalist and Radical Humanist perspectives of the four world-view model. The goal of this study was to broaden the discourse of breast cancer. Each chapter explains breast cancer from a unique perspective. The goal was not to critique the value of the literature within each perspective. Paulston (1996) believed work from one perspective must not be judged by the values and beliefs of another. It is easy to criticize and dismiss literature from one perspective from the viewpoint of another. A functionalist could disregard a humanist study on the basis that the sample size was too small. The gold standard for functionalist research is large randomized double blind studies, while the expectation for humanist research is comprehensive interviews with small numbers of subjects until no further information is solicited. The standards for functionalist and humanist research vary significantly, based on different values and rules. If work is to be judged, it must be done so by first understanding the values and rules inherent in the perspective.
Summary

By using the interview guide, (Table 1) literature that illustrated each perspective of the four world-view model was identified. The descriptions of the two dimensions, subjective versus objective and challenge versus change, that underlie the four world-view model were used to create the interview guide. The search for literature was wide-ranging, including a variety of materials. Not all literature on breast cancer was utilized, samples were selected to reflect several issues that were relevant to each perspective. The goal of this study was to use the four world-model as a framework for creating a broad and complex description of breast cancer, the intent was never to create an exhaustive description of breast cancer.
The functionalist perspective is the dominant way of viewing breast cancer. Most health care providers, health care agencies, government bodies and women with cancer view it from this perspective. Reality is objective, measurable and testable and society considered stable and neutral. Functionalist research focuses on ways of improving people’s health in the context of the current system. Breast cancer is viewed as a disease of abnormal cells that can be destroyed by surgery, radiation therapy and chemotherapy.

The amount of research from this perspective is staggering. In March 2001 a search on ‘breast cancer’ was performed using the Medline database. This is the most comprehensive database for articles on biomedical research. It was developed by the National Center for Biotechnology Information, the National Library of Medicine, and the National Institute of Health and is comprised of over 4000 biomedical journals published in seventy one countries, including Canada, United States, Australia, Britain, etc. There are over 11 million citations dating back to the mid-1960’s. The search in March 2001 found 7,470 breast cancer articles published between January 2000 and February 2001. Due to the immense amount of functional data available, the literature in this chapter will be limited to treatment guidelines, which are called “clinical practice guidelines”. Panels of recognized medical experts have created these using the most up-to-date research. These clinical practice guidelines recommend specific surgical, radiation and chemotherapy treatments for women with breast cancer.

It is estimated that 19,200 women in Canada will be diagnosed with breast cancer in the year 2000 and 5,500 women will die from it (National Cancer Institute of Canada, 2000). In the past 30 years there have been great improvements in breast cancer care: more accurate diagnosis and more effective treatment regimes. A woman diagnosed with early breast cancer now has a 95% chance of surviving five years (Ilivotto, Gelmon and Kuusk, 1995). The most common treatments for breast cancer are surgery, radiation and chemotherapy.

These recommendations have been taken from clinical practice guidelines published in Canada by the Cancer Care Ontario Practice Guideline Initiative (CCOPGI) and Australia by the National Breast Cancer Centre (NBCC). Prior to exploring this literature, the process for creating clinical practice guidelines, as well as the basic biology of breast cancer will be reviewed.

**Clinical Practice Guidelines**

Clinical practice guidelines are recommendations for treatments for health concerns. Panels of experts review up-to-date research to develop them. This process often takes over two years as thousands of research articles are assessed. Merit is assessed using
criteria informed by the functionalist perspective (see Table 2), with large randomized controlled studies deemed most credible. Evidence for each recommendation is graded on a scale of one to five, with level one being the best. These levels of evidence have been widely adopted throughout the health care field.

Table 2
Levels of Evidence Concerning Research Credibility

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level I</td>
<td>large randomized controlled trials.</td>
</tr>
<tr>
<td>Level II</td>
<td>randomized controlled studies that are too small to provide level I evidence.</td>
</tr>
<tr>
<td>Level III</td>
<td>non-randomized controlled or cohort studies, case series, case controlled studies, or cross sectional studies</td>
</tr>
<tr>
<td>Level IV</td>
<td>opinion of respected authorities or expert committee, as indicated in published consensus documents or guidelines</td>
</tr>
<tr>
<td>Level V</td>
<td>opinion of guideline committee members, based on their experience, knowledge of relevant literature and discussion with peers</td>
</tr>
</tbody>
</table>


Breast Cancer Basics

The goal of breast cancer treatment is to halt the growth and spread of cancer cells. By understanding the properties of breast cancer tumors, the most effective treatment can be provided. Basic descriptions of the properties of breast cancer will be discussed in this section.

Cancer and Metastasis

For a functionalist, all cancers are due to the same disruption in normal cell growth. Human cells reproduce in a regular pattern, dying off and replacing them as needed. Cancer occurs when the body's internal regulatory mechanism fails. This malfunction leads to uncontrolled growth and reproduction of cells. Sometimes this cell growth is so prolific it spills over into adjacent structures, so the tumor becomes attached to the skin, muscle and bones (Liu, 1999). Cancer can also spread via long microscopic tentacles of cancerous cells that radiate from the tumor. Occasionally cancerous cells break away
from the original site and spread to distant areas of the body, such as the liver, lung and kidneys. Here the cancer cells continue their rapid growth. This process of spreading throughout the body is called metastasis (Illivotto et al, 1995).

At the beginning of the 20th century, it was believed cancer spread in a circular pattern, radiating out from the primary site like spokes on a wheel. Later, in the 1950’s, it was discovered cancer could appear in distant organs, virtually leaping through the body. It is now believed breast cancer spreads through the lymphatic system, a drainage system closely integrated with the blood system. This spread of cancer is not orderly since it has been found in distant lymph collection sites, called lymph nodes, while being absent in nodes closer to the original tumor (Illivotto et al, 1995).

Staging of Breast Cancer

When a woman undergoes a breast biopsy, information on the size of the tumor and whether or not it has spread throughout the body and lymph nodes is collected. This information is compiled and used to determine the stage of the cancer. The American Joint Committee on Cancer developed a standardized staging system (see Table 3) which predicts the average five-year survival rate for women with breast cancer based on information that can be collected during a biopsy.

Table 3
Staging of Breast Cancer

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
<th>5-year Survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Tumor &lt; 2 cm, no metastasis, no cancer in lymph nodes</td>
<td>80 – 95%</td>
</tr>
<tr>
<td>II</td>
<td>Tumor 2 – 5 cm, no involvement of skin or chest walls. If one lymph node is involved, it must be movable (not affixed to other tissue)</td>
<td>50 – 70%</td>
</tr>
<tr>
<td>III</td>
<td>Advanced local tumor, fixed to skin or chest wall or presence of lymph nodes attached to structures in the axilla</td>
<td>30 – 60%</td>
</tr>
<tr>
<td>IV</td>
<td>Cancer spread beyond the breast and axilla, to lymph nodes above collar bone or distant organs</td>
<td>5 – 20%</td>
</tr>
</tbody>
</table>

Illivotto et al, 1995
Tumor Grade

The grade of the tumor is determined by the appearance of the cancer cells under the microscope. Cancer cells are checked to see how closely they resemble normal tissue. If the tumor cells look like normal cells, then the tumor is termed “low grade”. Cells that look markedly different from normal tissue are considered “high grade” (Lui, 1999).

Hormone Receptors

Breast cancer tissue is tested for estrogen and progesterone (hormone) receptors. These tests help predict whether or not certain hormones influence the growth of cancer. Women with positive results from these tests are more likely to have cancer that will respond to manipulation of hormone levels. Women with hormone positive tumors are also more likely to have a better overall survival rate (Lui, 1999).

Surgery

Breast cancer can be treated with either comprehensive total mastectomy or breast-conserving surgery (BCS) followed by radiation. Research has shown that for many types of breast cancer, these two procedures have the same long-term results. About 70% of breast cancer detected during mammography and 50% of cancer detected during breast self-examination or on physician examination are suitable for BCS (NBCC, 2000).

Breast conserving surgery, commonly referred to as a lumpectomy, involves removing the tumor as well as a rim of normal breast tissue. If the rim of tissue is clear of cancer, the tumor removal is said to have “clear margins”. This type of surgery is suitable for women who have only one tumor, and where clear margins are obtainable. Radiation therapy is always recommended to ensure that there are no microscopic tentacles of cancer left behind (Lui, 1999).

A total mastectomy involves the complete removal of the breast, including the nipple and the fascia (thin layer of tissue) that overlays the muscles. The underlying muscles and nerves are left intact. Mastectomy is required when the cancer is widespread in the breast, there are multiple tumors, clear margins are not obtainable with BCS, or there are contraindications for radiation therapy. Women who will likely be harmed by radiation treatment, such as those women who are pregnant or have disease that will be exacerbated by radiation, are not candidates for BCS since radiotherapy is not a safe treatment. Women may chose mastectomy over BCS because radiation treatment is only offered in larger cities (NBCC, 2000). Radiotherapy can be time consuming, logistically difficult and costly for women if they live a great distance from a treatment centre. Some women prefer not to have radiation therapy as they are concerned about the possible side effects such as swelling, pain, skin discoloration and fibrosis (hardening) of the breast tissue (CCOPGI, 2000).
The choice of BCS versus mastectomy usually depends on individual circumstances and personal preference. Some studies have demonstrated better outcomes from BCS, but this is not consistent through all studies. Several studies have shown that women undergoing BCS have less problems with sexuality and body image post-treatment (NBCC, 2000). Other studies have shown that there is no difference in quality of life, depression and anxiety scores between these two groups (CCOPGI, 2000).

The National Institute of Health Consensus Conference in 1992 recommended BCS as the preferred treatment because it provided equivalent survival while preserving the breast. Six prospective randomized trials have shown that the removal of only the tumor, leaving most of the breast intact, results in the same survival and distant metastasis rate as total mastectomy (CCOPGI, 2000; NBCC, 2000).

**Radiation Therapy**

Radiation therapy after breast conserving surgery significantly decreases the incidence of local recurrence of cancer. This therapy does not seem have an effect on long-term survival post-BCS. Radiation therapy is the use of high-energy rays that damage all cells in the area irradiated. Normal cells have the ability to repair themselves while cancer cells do not (Ilivotto et al, 1995).

Five studies have shown radiation post-BCS significantly decreases the risk of local recurrence of cancer. These studies included women with various sizes of tumors, lymph node involvement and length of study follow-up. Table 4 summarizes these studies and shows improvement in outcomes for the radiated group.

**Table 4**

<table>
<thead>
<tr>
<th># of Subjects</th>
<th>Length of Study</th>
<th>Lymph Nodes</th>
<th>Tumor Size</th>
<th>Recurrence Rate During the Study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>No Radiation</td>
</tr>
<tr>
<td>2105</td>
<td>12.5 years</td>
<td>Positive</td>
<td>&lt; 4 cm</td>
<td>41%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative</td>
<td>&lt; 4 cm</td>
<td>32%</td>
</tr>
<tr>
<td>381</td>
<td>5 years</td>
<td>Negative</td>
<td>&lt; 2 cm</td>
<td>18.4%</td>
</tr>
<tr>
<td>837</td>
<td>7.6 years</td>
<td>Negative</td>
<td></td>
<td>35%</td>
</tr>
<tr>
<td>579</td>
<td>3.3 years</td>
<td>Neg./Pos.</td>
<td>&lt; 2.5 cm</td>
<td>8.8%</td>
</tr>
<tr>
<td>585</td>
<td>6 years</td>
<td></td>
<td>&lt; 4cm</td>
<td>24.5%</td>
</tr>
</tbody>
</table>

Cancer Care Ontario Practice Guideline Initiative, 2000
The probability of local recurrence without radiotherapy is less when the tumor is smaller than 2 cm in diameter, and when women are older than 50 years of age. However, omission of irradiation after breast conserving surgery increases the risk of local recurrence significantly, even in the lowest risk cases. Both the Canadian (CCOPGI, 2000) and the Australian (NBCC, 2000) clinical practice guideline recognizes that omission of radiotherapy after breast conserving surgery increases the risk of local recurrence.

Outcome-oriented research has clearly shown a decrease in recurrence post-radiotherapy for women who have had BCS, but an optimal dose and schedule for irradiation has not been established. Of the five studies quoted in the Canadian (CCOPGI, 2000) clinical practice guideline document regarding irradiation post-BCS, no studies used the same dose and schedule of irradiation. Canadian clinical practice guidelines outline the most common schedule for irradiation, but make no recommendations on what schedule should be used due to the absence of research on this topic.

Research has shown that higher daily doses of irradiation, as well as higher total doses administered on a shorter time schedule, result in more side effects. Irradiation doses need to be large enough to prevent recurrence, but kept to the smallest dose effective to prevent unnecessary side effects. Common short-term side effects are redness of the skin and fatigue, these side effects usually resolve within three to six months. Mild to moderate long-term effects of irradiation are relatively rare: intermittent pain in the breast (20%), redness of the skin (6%), swelling of the breast (3%), hardening of the breast tissue (1.6%), and bruising over the breast area (13.8%). Severe long-term ill effects of irradiation are extremely rare; lung inflammation (0.7 – 7%), inflammation of the heart lining (0 – 0.3%), rib fracture (1.1 – 1.5%), significant arm swelling (1%) (CCOPGI, 2000). There has been some concern that radiotherapy can cause a secondary cancer. In six studies involving approximately 150,000 women treated with radiotherapy for breast cancer there was a non-significant increase in secondary cancers (NBCC, 2000). In the past there was an increase risk of late cardiac deaths in women who had undergone radiotherapy. In more recent studies, where lower doses of irradiation were administered there does not appear to be an affect on the heart. These studies have had a relatively short follow-up (less than ten years) therefore more time is needed to determine if modern radiation techniques cause long term heart damage. (NBCC, 2000; CCOPGI, 2000).

**Chemotherapy**

Historically chemotherapy was defined as any drug or medicine that treats disease. Today chemotherapy is widely referred to as drugs used to treat cancer. Chemotherapy is given to women at risk of recurrence of cancer. Chemotherapy works by traveling through the blood stream and reducing the growth of cancer cells that cannot be detected, but are presumed to be throughout the body. There are dozens of chemotherapy drugs, each works in a different way, so usually several are given at the same time (Ilivotto et al, 1995).
Women at high or moderate risk for recurrence of breast cancer usually receive chemotherapy. Risk is determined by information collected through surgery and breast cancer tumor biopsy (Table 5).

### Table 5
Criteria to Determine Need for Chemotherapy in Breast Cancer Treatment

<table>
<thead>
<tr>
<th></th>
<th>Low Risk</th>
<th>Moderate Risk</th>
<th>High Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk of Recurrence after 10 years</td>
<td>10%</td>
<td>60%</td>
<td>90%</td>
</tr>
<tr>
<td>Must have all of the following:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tumor Size</td>
<td>&lt; 1 cm</td>
<td>&gt; 2 cm</td>
<td>&gt; 5 cm with one or more cancerous lymph nodes</td>
</tr>
<tr>
<td>Cancer in Nodes</td>
<td>No</td>
<td>Yes - 1 or more</td>
<td>Yes - 10 or more</td>
</tr>
<tr>
<td>Invasion into Adjacent Structures</td>
<td>No</td>
<td>Yes - lymphatic vessels, blood vessels, or nerves of breast</td>
<td>Yes - skin and chest wall</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Cancer Care Ontario Practice Guideline Initiative, 2000

Chemotherapy, including hormonal manipulation through anti-estrogen drugs, can decrease the annual risk of recurrence and death for women with both node positive and node negative breast cancer. There is an approximate 30% reduction in recurrence and a 20% reduction in risk of death. This means a woman with node positive breast cancer would reduce her risk for recurrence in 10 years from a 60% risk to a 42% risk. For women with node negative breast cancer the risk for recurrence would drop from 10% to 7% (Illivotto et al, 1995).

Drug trials test the effects of different combinations, doses and lengths of treatment of chemotherapy. Research has determined that chemotherapy regimes of several months'
duration are more effective than those regimes of only one-month duration. There are similar recommendations in the Canadian (CCOPGI, 2000) and Australian (NBCC, 2000) guidelines for combinations, doses and schedules for chemotherapy agents. Lower doses of chemotherapy have been shown to be ineffective, therefore both the Canadian (CCOPGI, 2000) and Australian (NBCC, 2000) guidelines recommend higher intensities of drugs be maintained. High dose chemotherapy, which is above conventional levels, is still considered experimental and is extremely expensive and potentially hazardous. Tamoxifen, an anti-estrogen agent, has been shown to significantly improve recurrence-free survival in women over 50 with estrogen positive tumors. Benefits for all ages of women with estrogen positive tumors have been shown. It also reduces the incidence of breast cancer in the other breast. Large studies on Tamoxifen have identified optimal dosing of this drug: 20 mg/day for 2 - 5 years. There is no benefit to continuing the treatment after 5 years (NBCC, 2000).

Summary

Within a functionalist perspective, breast cancer is treated with surgery, radiation and chemotherapy. Women with breast cancer today have a better chance of surviving than their mothers or grandmothers did. Due to the advances in treatment of breast cancer, most women are able to return to their pre-cancer life, with their health intact. As research on breast cancer continues to discover more about how cancer grows and spreads, more effective treatments for breast cancer will be developed. Early work on genetic markers and “smart drugs” that can seek out cancer cells promise to change the face of breast cancer treatment in the next 20 years. Within this perspective, the hope is that eventually all women with breast cancer will be cured.
CHAPTER FIVE

HUMANISM

My sister-in-law was diagnosed with breast cancer in 1998 - it completely changed her life. She only visits her children sporadically now, she is estranged from her own family and she has given up her job to pursue a career in writing. When we talk about her cancer, we do not spend time talking about the cells and the chemotherapy, we talk about why she got cancer and how it has changed her life: it gave her the courage to make changes, to pursue new ideas, and the freedom to begin again.

Humanism is concerned with explaining phenomena from the viewpoint of the people affected by it. Humanist researchers try to understand how the individual creates, modifies and interprets the world in which they find themselves. Research focuses on understanding how the world "is" for the person experiencing it, not how it "could be". Society is rarely discussed, and if it is, is described as relatively stable and functional. In a stable and functional society, status quo is maintained, there is voluntary and spontaneous agreement of opinion, social integration and cohesion of members of society is apparent and human needs are satisfied within the current social system. When looking at breast cancer through a humanist lens, researchers attempt to understand the way women with breast cancer experience disease.

More than ever before, women are talking about their experiences of breast cancer. A host of popular magazine articles and books have been written about it. Usually these stories are written about famous women with breast cancer - non-famous women often stay quiet about their disease, only talking about it with family, close friends or other women with breast cancer. This chapter uses the literature to explore three different ways that non-famous women talk about their experience with breast cancer: cancer as enemy, cancer as challenge, and cancer as transformation.

Cancer as Enemy

For many women breast cancer is synonymous with fear, sickness, and death. This is due to either having known or read about someone who had died from it. A diagnosis brings the issue of mortality to the forefront, and in our death denying western culture, this is a difficult issue for most women and their families. For many women, breast cancer means suffering and eventual death, fear of recurrence, and loss of normal life.

Suffering and Eventual Death

Women with breast cancer often know of other women who have been sick, suffered and eventually died from their cancer. In a study done by Utley (1999), eight women with breast cancer were interviewed about what it meant to them. One of the themes that
emerged was "cancer as sickness and death". Statistically most women with breast cancer will survive beyond five years, but all women in this study knew others who had died of breast cancer. One woman in the study had four neighbors die from cancer while others spoke about sisters, cousins, and aunts dying. Only one woman spoke of knowing a breast cancer survivor. Statistics show that breast cancer is a treatable disease, but for many women with cancer it is a killer.

When asked to speak about what cancer meant to them, women often spoke about the inevitability of dying from their cancer: "You know that if you have breast cancer, your life is going to be shorter than everybody else’s. I thought I was going to be hurting and sick for the rest of my life" (Utley, 1999, p.1521).

Fear of recurrence

Breast cancer is one of the most treatable cancers, yet women suffer from recurrence five, ten or twenty years later. Women with breast cancer know about the potential for recurrence and live with fear of it for the rest of their lives. Women in the Pelusi (1997) study explained that the fear of recurrence becomes more real each time they heard of someone having a cancer recurrence. Unfortunately these women can never assume cancer will not return. One woman described her fear of potential recurrence: "I desperately wanted some reassurance from [the physician] about the future, that I would never have to worry again . . . He said, "I can’t tell you that" (Pelusi, 1997, p. 1345).

Breast cancer can spread to other areas of the body, so women often question every change they feel:

Every little ache and pain makes me nuts. Until you get cancer those little pains don’t mean anything . . . You’re overworked, tired, getting older . . . but now things like that could mean [the cancer] is back. (Pelusi, 1997, p. 1345)

Some women believed breast cancer would shorten their life. In the Pelusi (1997) study women spoke about not expecting to live as long as other women. Breast cancer is something that affects the present, the immediate and the distant future. Ferrell, Grant, Funk, Otis-Green, and Garcia’s (1998) study also discovered the fear women had of having a terminal illness:

... I guess I do feel that I am terminal ... you have this kind of sense of vulnerability ... every once in a while when I am going to sleep the sort of magnitude of what has happened to me hits me, but it's not something that I carry around with all the time, carry around with me, every day every minute ... (Ferrell et al., 1998, p. 2).
Loss of Normal Life

For many women breast cancer changes their lives forever. They no longer feel that they live a “normal life” or that they can ever return to their previous life. In Pelusi’s (1997) study, women described this as a “sense of abandonment” in relation to their previous life. The cancer had made them abandon a life that they and their families were comfortable with. Others expected them to return to a normal life, but these women viewed that as an impossible expectation.

Those old normals [in life] don’t exist anymore, it’s gone . . . Now what we have is new normals . . . Try to explain that to your family and friends . . . they just don’t get it . . . Your hair comes back, you go to work again . . . so it’s supposed to be like before . . . You want it to go back to what it was like before, but you never will . . . The cancer took my old life away (Pelusi, 1997, p. 1347).

Long term side effects from cancer treatment also created a loss of normal life. In a study by Carter (1997), women with lymphedema, a chronic, non-curable swelling of the arm, discussed their life after cancer. These women were self-conscious about their swollen arms and described themselves as “ugly”, “freak”, “frumpy” and “wicked witch”. In an attempt to appear normal, these women concealed their swollen arms with special clothing. They also avoided social gatherings such as cocktail parties, summer getaways, and pool activities where they would need to expose their ‘imperfect image’. To minimize the swelling, walking, golfing, tennis, heavy lifting, typing, and excessive writing were eliminated from their lives. This change in activity prevented their participation in many social and work activities:

[the lymphedema] is a . . . physical burden. I even have a hard time going for a walk because as soon as I’m swinging my arm, it swells up and is uncomfortable. So we tend to not even go for a walk (Carter, 1997, p. 880).

The fear of death, of cancer recurrence and loss of normal life all contributed to women experiencing cancer as the enemy. Breast cancer changed these women’s lives, they could never return to their normal life, life before cancer.

Cancer as Challenge

When a crisis occurs, some people immediately give in to it because they are unable to find hope for the future; whereas others, determined to go on living, mobilize some inner power or strength. For some women, cancer is seen as a challenge, a temporary barricade that they need to address and eventually move beyond (Utley, 1998). Many magazine articles have been written about famous women’s battles with breast cancer. These
stories discuss when they were diagnosed, what treatments they had, and how they fought the battle with cancer and “won”. “Cancer as challenge” focuses on women’s experiences of accepting the diagnosis, returning to normal activity patterns, returning to a normal body image, and putting cancer behind them.

Accepting the Diagnosis

For many women the first step in the cancer journey started after their diagnosis when they began to ask psychologically and spiritually painful questions. These questions included “why did this happen”, “why do bad things keep happening to me”, “why does God let bad things happen”, and “did I do something wrong” (Taylor, 2000). In Taylor’s (2000) study women described this time as a difficult phase, marked by tears, depression and feeling overwhelmed with desperation. One woman described her experience of trying to make sense of the breast cancer diagnosis:

All I think about is why did this happen? . . . I haven’t been able to make sense of it so far. I think that is why I’ve stayed so depressed and confused and everything. If I could find meaning for it, or some way I could make sense of it, I’d probably feel better about myself (Taylor, 2000, p.785)

Many women eventually accepted there is no answer to the question “why me”? Some women turned to God and accepted that breast cancer is part of God’s plan:

Yeah, sometimes I [say] ‘Why me?’ but it’s like I say, only God knows . . . It don’t bother me because I feel as though God is the only one, He handles – He’s over everything, so it’s just like you can’t worry or question Him on what’s going on. So I don’t know. I try not to think about it . . . there is no answer for what can happen (Taylor, 2000, p. 785).

Others took on a philosophical viewpoint of ‘well, why not me?’:

Now I just feel that there is no sort of rationale for most things . . . I think that there are good things and bad things that happen to you. And, like I say, I could have either sat there and cried for the rest of my life or could’ve just gotten on with it, and that’s what I chose to do (Taylor, 2000, p. 785).

Once women accepted there is no answer to the question “why me”, they began to work on returning to normal in terms of activities and body image.

Returning to Normal – Activity Patterns

For many women, and their families, “getting back to normal” as quickly as possible is an important part of coping with cancer. Getting back to normal means a state that is safe, stable and free of health problems and vulnerability (Hilton, 1996). Most families in the Hilton (1996) study viewed breast cancer as a temporary and short-term problem, while
some experienced it as a continuing long-term problem that delayed return to normal family life.

Some families hid the disease from others in an effort to protect themselves and others and to minimize the situation. Not talking about cancer helped control their emotions and prevented them from having to deal with the reactions of others:

We didn’t want people to know that much because we didn’t want them coming around. We didn’t want anything to change . . . I didn’t tell anyone at work except for just the immediate people in the office. If everybody in the shop found out, they’d treat me differently, and I don’t want to be treated differently. I want to be treated just like I’ve always been treated. (Hilton, 1996, p. 610)

Many families continued on as if nothing has happened in an effort to provide stability for the family. Families in the study by Hilton (1996) spoke about returning to normal after cancer. Some families found an early return to normalcy desirable, while others saw it as problematic. Some families expected women to maintain the status quo, some women found that they were not healthy enough to continue with their normal responsibilities. This inability of women to perform regular activities created family tension. In other families, where the roles and responsibilities had been shifted during the treatment phase, children, especially teenagers, were angry about the sudden decrease in responsibility and independence when their mother returned to health:

We ran the whole house . . . we were independent, on our own . . . mom was out of commission, and then she got back into commission, and her rules are her rules, but I don’t think she realized that we’re all sort of grown up a bit now. (Hilton, 1996, p. 609)

Some families experienced a smooth transition back to normal life, many families found the journey back to normal difficult. Often, members of the family and woman with cancer had different expectations about the process of getting back to normal. Sometimes the woman felt unable to return to normal or the family did not allow her to take back previous responsibilities (Hilton, 1996). Getting back to normal was difficult when there was conflicting expectations of family members.

Returning to Normal – Body Image

Returning back to normal as soon as possible was a priority for many women with breast cancer. In Neill, Armstrong, and Burnett's (1988) research women who had recently undergone reconstructive surgery were interviewed. These women viewed it as a choice that allowed them to return to normal without jeopardizing their treatment and recovery. For them, normality meant appearance, body integrity, awareness of social self, and physical activity. Many women felt they lacked “wholeness” after their breast removal. Women frequently spoke about their need to look and feel “normal” and to put the cancer
experience behind them. “Regaining normal” meant looking normal and no longer being bothered by a lack of wholeness.

I was afraid that I would always feel very awkward not look normal. And that pushed me into doing the reconstruction, so I would look more normal. And in that way, I would also lead a more normal life. And not have it in my mind always, oh, look, I am so handicapped, I am not whole. So I have decided to do it ... I will feel complete then (Neill et al., 1988, p. 748)

Choosing reconstruction was viewed as the most natural choice to achieve the goal of returning to normal. Having only one breast, or using prosthesis was seen as being unbalanced or lacking wholeness.

All I wanted was to get back to normal as soon as possible, and I wanted to be cured . . . there was never any consideration of not having [reconstruction]. I don’t know why any woman wouldn’t have it . . . there’s just no point in not looking normal and feeling normal when you’ve got these options in today’s world (Neill et al., 1998, p.748).

Reconstructive surgery helped women in the Neill et al. study gain a feeling of normalcy.

Putting Cancer Behind Me

For some women it was important to view cancer as something to “put behind them”, something they no longer had to think and worry about. Even though breast cancer can recur five, ten, twenty years later, some women in the Ferrell (1998) study viewed it as a short-term disease that ended when their treatment ended. They referred to themselves as women who “had” breast cancer, or as breast cancer “survivors”. In an effort to seek normalcy they had put breast cancer behind them, never to be revisited. Some women depended on their faith to help them get on with their life post-cancer, while others had personal beliefs that prevented breast cancer from becoming a focus of their life: “I have faith that this cancer is not going to return, so I have that faith that I can go on and live my life. I want to go on with my life and I don’t want to think about it” (Ferrell et al., 1998, p. 3). “I am a woman who ... had breast cancer. That’s it. I’m not going to be consumed by it. I’m not going to alter my life. I live my life” (Ferrell et al., 1998, p. 3).

Accepting the diagnosis, returning to normal activities, returning to normal body image and putting cancer behind them all contributed to women viewing cancer as a challenge. Cancer was viewed as something to “get over” as quickly as possible in an effort to return to normal life. Cancer is thought of as another challenge in life that must be “gotten over”.
Cancer as Transformation

For some women, breast cancer was viewed as a positive experience: it provided an opportunity to extend themselves and to take on broader life perspectives, activities and purposes (Coward, 1991). These positive aspects of breast cancer developed over time, as women learned from their cancer experience.

Breast cancer is a traumatic event in any woman's life. When a woman is diagnosed with breast cancer, her assumptions about her world are shattered. People ordinarily function on the basis of an illusion of relative safety and security. We know that bad things happen, that people do get cancer, but we are apt to believe “it can’t happen to me.” This illusion of invulnerability is dramatically shattered by the experience of a cancer diagnosis. When assumptions are shattered, we need to reconstruct our worldview so it can encompass the trauma we experience (Timko and Janoff-Bulman, 1985, Janoff-Bulman, 1992). This reconstruction leads to a more mature way of viewing the world. This process is comprised of balancing thinking about the painful subject and avoiding painful thoughts. Strategies women use to reconstruct their assumptions include making comparisons (e.g. “it could be worse”), self-efficacy (e.g. “because I caused it, I can prevent it from happening again”), and finding positive meaning in the suffering (Janoff-Bluman, 1992). Finding a positive meaning leads to thinking about the world, and acting in the world in new ways: a personal transformation. This section will discuss some aspects of personal transformation: changing priorities, a new understanding of self, and reaching out to others.

Changing Priorities

In the study by Timko and Janoff-Bluman (1985) a diagnosis of breast cancer created a feeling of uncertainty about the future; “will it be cured?”, “will it come back?”, “how long will I live?”. The most common problem for breast cancer survivors was fear of recurrence (Timko and Janoff-Bluman, 1985). Some women used this fear in a positive way by creating quality for the remainder of their life by changing their priorities. These women recognized that time must be used wisely, since breast cancer could recur again at any time. Changing their priorities meant allowing themselves to take pleasures in the details of their life and recognizing the importance of family and friends.

Women in the Ferrell et al. (1998) study frequently spoke about changing their priorities so they could appreciate their life more fully. Some women changed what they were doing; they stopped doing things they did not enjoy and began to look for new experiences to try.

I don’t have to worry about anything, that’s the least of my concerns, and the same at the office. If something happens, it will get done and it truly will and it will be okay. Things are not as serious as what they used to be. I used to be a perfectionist, things just to be so. Things are not that important anymore, it’s
more important to get out at lunch, to see people not to stay in. To experience more things, as many things as you can. It's just like quilting, I never quilted before and I can't even sew, but I'm quilting (Ferrell et al., 1998, p.7)

In the Taylor (2000) study some spoke about realizing the significance of people in their lives. Family and friends became a new priority: “I've realized how of little importance toys are, having money and things like that, and how important my friends are and my family. It's put it all in very clear perspective now” (Taylor, 2000, p. 786).

In the Pelusi (1997) study some women continued to do what they were currently doing, but with new intentionality and enjoyment: “Cancer has given me a chance to see what is really important to me . . . . I was so shallow before . . . . my relationships and work have all taken on special meaning” (Pelusi, 1997, 1347).

Re-prioritizing life led to a profound appreciation and joy of life for the women in the Taylor (2000) study. Some women described cancer as a gift, something that helped them see their world in a new light, bringing joy out of a crisis:

I see things in a much more positive light. I mean you get up in the morning and I'm glad there's a new day. And, I'm thankful for my family more . . . and definitely more aware of the beauty around me . . . . There is a greater sense of joy, I don't know how else to put it, in everything. Whether it is being with the family, experiences at work, just walking out and seeing the flowers and the birds and that sort of thing (Taylor, 2000 p. 786).

The potential proximity of death, through a breast cancer recurrence, created a feeling of immediacy. Potential lack of time had a direct influence on how women lived their lives. Some felt that present time expanded and lived in the present, rather than waiting for their future (Nelson, 1996). They appreciated the present, and lived each day fully as one woman described “...you just have to take one day at a time, and live each day as if it were your last, like they say” (Ferrell et al, 1998, p.7). In the Utley (1999) study a woman echoed this sentiment “... it makes you appreciate things you don’t pay much attention to before you have a problem. It made me appreciate the things I took for granted”. (Utley, 1999, p. 1522). Other women used their time to try new experiences, instead of waiting for some distant future that might not come. “I've done things that I've been wanting to do for a long time, but hadn't gotten around to . . . because of the possible time pressure, I better get on with it because I may not have the amount of time that I thought” (Taylor, 2000, p. 786).

These women found new ways of creating a quality life, for each woman that meant something different. Breast cancer was the impetus for change; the uncertainty of the future challenged them to learn new ways of being in the world. These women cherished their lives with new passion.
A New Understanding of Self

Breast cancer has helped some women learn about themselves and given them the opportunity to explore new aspects of their person. Many women learnt they have incredible inner strength. Other women increased their spirituality. Living with uncertainty is an integral part of breast cancer, and many learned how to successfully live with this difficult reality. Breast cancer has even been viewed as a liberating or positive experience, one that provided them with an opportunity to grow.

Breast cancer provided the impetus for many women to review their lives and explore who they were before the cancer, who they were currently, and who they wanted to be in the future. Many survivors spoke about venturing into new ‘self’ territory:

I always thought that I knew who I was and what I stood for, then cancer struck. I realized I knew very little, but thanks to cancer, if you can say thanks to cancer, I’m who I want to be and proud of who I am and how I live my life now (Pelusi, 1997, p. 1348).

Some women in the Utley (1999) study described breast cancer as an experience that provided them with an immense challenge that required incredible inner strength. Once diagnosis and treatment had passed, these women looked back at the experience and realized just how strong they were:

Cancer changed my life forever. I realized that I had an inner strength that I could call upon when needed. I didn’t know how strong I was. My experience with breast cancer gave me insight into who I am. I was a person. I could fight. I had strength. I had this inner power in myself that I could make decisions that would carry me through life (Utley, 1999, p. 1522).

Breast cancer often created intensified spiritual awareness. Women more frequently turned to God for inner peace and support: “I became more in touch with God and spirituality. I became more quieter, within myself you know” (Taylor, 2000, p. 786). Women who had previously been religious often increased their connection with God through the illness experience. “It did change me, spiritually you are more in tune. I’m more in tune I feel . . . and more aware of God and what He has planned for me . . . I mean it in a truly spiritual sense” (Taylor, 2000, p. 786). Some women found their reconnection with their religion a benefit of breast cancer. One woman described returning to religion as the best thing that happened from her cancer (Taylor, 2000). For another woman, breast cancer was a time to begin a relationship with God:

My whole life changed because I thought I was going to die. I thought ‘I’m going to end up dying from this so make the best of my life’. . . . I turned to God. Now I would talk to God, not just in prayers, and the more I talked to Him, the more friendly we became (Utley, 1999, p. 1522).
Living with the uncertainty of breast cancer was very difficult for most women. This uncertainty challenged women to learn new ways of being in the world. Self-exploration was a necessary step in learning to live with the uncertainty (Nelson, 1996). One way of living with the uncertainty was to focus on the positive aspects of life, to discover how precious and meaningful life could be (Nelson, 1996). Another way of learning to live with the uncertainty was to let go of control; not ask why things happened and accepted that things do not always work out as expected (Coward, 1991). Some women learned to coexist with fear, to come to terms with death, and to no longer worry about death, they just focused on enjoying their lives (Coward, 1991). One woman in Coward’s study spoke about not being afraid of death, she described death as “the reward, the rest, the peaceful sleep” (Coward, 1990, p. 165).

Some women experienced breast cancer as a liberating experience. In the Nelson (1996) study, a woman described being less sensitive to social pressures as she learnt new ways of living with the uncertainty of breast cancer. She felt less constrained by what was expected and freer to express ideas and behaviors congruent with their thoughts and feelings.

Cancer is so liberating for me. I can say anything I want now. I don’t hold back, I say what I really think . . . I could never have done that before. But I was a pleaser and I wanted everybody to be happy. I didn’t want to give a bad appearance. I wanted to be a good neighbor. That is over. (Nelson, 1996, p. 69).

For some women, breast cancer provided an opportunity to learn. They realized that they had immense inner strength, that spirituality was an important component of their lives that they could live with uncertainty. For some, cancer could even be a liberating experience.

Reaching Out to Others

Once treatment for breast cancer had been completed, some women looked for ways to help others. One woman described this experience as; [Breast cancer has] made me a much better person. It’s made me aware of people, being sensitive to their needs . . . So, while I’m here, I’m going to help as many people as I can”. (Taylor, 2000, p. 786). Women reported that their cancer experience had made them more sensitive to the tragedies of others. Activities of compassion were generally targeted to other women with breast cancer or to educating others about breast cancer prevention. Some women became politically active, while others led breast cancer support groups. Some women simply took the time to talk to other women with breast cancer about how to cope (Taylor, 2000).

These women who had gone through the cancer experience felt they had precious gifts that only they could give to other women: information and hope. Giving information and
hope to others was viewed as a way of giving back after so many people had helped them during their treatments.

I knew I could help . . . I'd been there . . . I know what it is like . . . It's so different to hear about it from [someone with cancer] who truly knows that from someone who thinks they know [health care providers, family, and friends]. (Pelusi, 1997, 1349)

A wonderful benefit of helping others was an increase in sense of personal worth. Helping others gave these women a sense of purpose, an increase in self-confidence, and validation of self-worth. One woman remarked that although she gave much of herself, she believed she received more than she gave (Coward, 1990).

By changing their priorities, developing a new understanding of self and reaching out to others these women viewed breast cancer as a transformation. They were able to create something positive out of this crisis.

Summary

Within a humanist perspective there are a variety of ways women have learnt to live after their cancer treatment is completed. For some women breast cancer is viewed as the enemy, something to fight. These women often refer to themselves as breast cancer survivors; they have taken on the battle of cancer and survived. Other women view breast cancer as a challenge, something to “get over”, “get past” and “get beyond”. These women describe themselves as “having had breast cancer”. This tells others that their breast cancer was a challenge in their life that they have gotten past it. Other women describe their breast cancer as a transformation, an opportunity to re-evaluate their life. These women often refer to themselves as women “living with breast cancer”. This label is similar to the one AIDS activist’s use, “people living with AIDS”. For these women, breast cancer has been embraced into their lives, and both the negative and positive aspects of it have been recognized and incorporated into their being. There are many different ways women with breast cancer view their disease, and cancer as enemy, cancer as challenge, and cancer as transformation are three of the common ways women with breast cancer describe their experience from the humanist perspective.
CHAPTER SIX

RADICAL FUNCTIONALISM

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever does.
- Margaret Mead

Radical functionalists view the world objectively and believe that society is constantly assaulted with modes of domination and deep-seated structural conflict. Elites control information and material resources to enhance their power, at the expense of the needs of the underclasses. The goal of radical functionalism is to modify society through access to information and changes to rules and regulations.

When looking at breast cancer through a radical functionalist lens, objective data can be found to show the effect that physicians, large corporations and health care organizations have on breast cancer care. Even though immense amounts of money have been earmarked for biological breast cancer research, the number of breast cancer cases continues to rise every year and the survival rate has had only modest improvements. Research and treatments are not provided to best meet the needs of women with breast cancer but rather as a way to enhance the position of the power elites. In the past ten years a small, but very vocal, group of women who have breast cancer have created an activist movement. These women view breast cancer from the radical functionalist perspective. Their priority concerns are increase in access to information and changes to rules and regulations. This chapter will review the objective data concerning the lack of progress in breast cancer care as well as three priority issues for radical functionalists; accurate and comprehensive information for women with breast cancer; safer less invasive treatments; and more research on the cause of breast cancer, specifically environmental links to cancer. Radical functionalists pursue actions that put the needs of women with breast cancer ahead of the needs of physicians, researchers, health care organizations, and large corporations.

Prevalence and Causality

The American Cancer Society (ACS), one of the largest cancer corporations in the world, wants the public to believe that we are “winning the war on cancer”. ACS’s advertising campaigns reassure people their donations have helped develop technologies that have significantly decreased the number of people who die from cancer. The ACS implies it is only a matter of time until cancer is eradicated. The statistics show that the number of cases of breast cancer is increasing every year, and that many people are still dying from it. Radical functionalists see these statistics as fodder for their fight to change the way breast cancer care is provided. The current practice of cancer care has not made
significant advances in the survival of women with breast cancer, and still very little is known about what causes breast cancer and how it can be prevented.

Prevalence

Breast cancer is the most common type of cancer among Canadian women, and the second leading cause of cancer death. For many years, breast cancer was the number one cause of cancer deaths for women, but now lung cancer has surpassed it. In Canada, breast cancer still claims many lives every year. An estimated 19,200 people will be diagnosed with breast cancer in the year 2000, and 5,500 of them are expected to die from it (National Cancer Institute of Canada, 2000).

Even though the ACS assures us that the war on cancer is being won, the incidence of breast cancer continues to increase and the survival rate has seen very little improvement (Table 6).

Table 6
Age Standardized Incidence Rates for Breast Cancer

<table>
<thead>
<tr>
<th>Year</th>
<th>Incidence*</th>
<th>Death*</th>
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<td>1995</td>
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<td>28.7</td>
</tr>
</tbody>
</table>

* per 100,000
National Cancer Institute of Canada, 2000

Breast cancer is one of several cancers that have risen in incidence rate since the end of World War II. A woman born in the United States between 1947 and 1958 has a three times greater chance of developing breast cancer than her grandmother did at the same age. There has been a 1 to 2% increase in breast cancer every year since 1940. In 1991, breast cancer cases of women over 65 years of age had increased by 40% since 1971 (Canadian Cancer Statistics, 2000).

Equally as disturbing is that the death rate from breast cancer has not had any significant improvement in the past 30 years, even though large amounts of money have been put into the breast cancer research coffers. A woman diagnosed with breast cancer in 1995 had only a slightly improved prognosis than a woman diagnosed with breast cancer in 1971.
Risk Factors

When it comes to determining the cause of breast cancer, almost 50% of women have no identifiable risk factors. Only 50% of women with breast cancer have high-risk indicators present. High-risk indicators are: early menarche, older age at birth of first child or childlessness, late menopause, and a sister or mother diagnosed with breast cancer (Love, 2000). There has been some preliminary research done linking a high fat diet with increased risk of breast cancer, but the results from these studies are inconclusive (Love, 2000).

There does appear to be a trend in worldwide distribution of breast cancer, with industrialized western countries having a higher rate of breast cancer than Asian countries and countries in the developing world. In 1998 Ireland, Denmark, and the Netherlands had the highest rates of breast cancer death while China and Albania had the lowest rates of breast cancer death (American Cancer Society, 1998). Japanese women have a very low risk of breast cancer, yet when they immigrate to North America their risk for breast cancer increases significantly. Some researchers are hypothesizing that this is due to change in diet, while others are questioning the environmental links to cancer (Batt, 1994).

Much work has been done lately on identifying the genes for breast cancer. Two genes for breast cancer, BCRC1 and BCRC2, have been identified in the past few years. It is believed that about 5 – 10% of all breast cancer cases are caused by genetic mutation, with BRCA1 and BRCA2 accounting for about half of these cases (2.5 - 5% of all breast cancers) (Rosser, 2000).

Even though 50% of breast cancer cases cannot be linked to high risk indicators, breast cancer prevention research has had minimal funding. The largest prevention study currently funded by the American government is the Tamoxifen study, which is a study to determine if synthetic hormone replacement will prevent breast cancer. Only 2.5% of breast cancer research funding have been designated for research on environmental exposure and breast cancer (Boehmer, 2000). Most research funding is for enhancing the effectiveness of treatments, yet the breast cancer rate continues to grow. Breast cancer activists, and many women with breast cancer, want more research on determining the cause and prevention of breast cancer so their daughters and granddaughters will not be have to be treated for breast cancer.

Information is Power

In 1974, Rose Kushner, a medical research assistant and journalist, discovered she had breast cancer. At the time there was very little accurate information about breast cancer available for the public; it was in the professionals’ domain. Physicians made the decisions and patients followed their directives. Physicians, pharmaceutical companies, and health care organizations prevented women from knowing about their own bodies
and their own diseases. All the power resided with the physician and the organizations (Kushner, 1982). Since Rose Kushner wanted to be involved in making decisions about her body, she investigated care options thoroughly. She wrote about her experience with breast cancer as well as an extremely comprehensive summary of breast cancer treatment in her 1982 book 'Why Me'. She believed that if women were to make informed decisions about what treatment they would receive, they needed accurate and comprehensive information about breast cancer treatment written in a way that they could understand. Rose Kushner investigated and wrote about risk factors, prevention, screening mammography, breast self-exam, radiotherapy, surgery, and research trials. The most up-to-date, worldwide findings were explained clearly in her book. This book was the first comprehensive summary of breast cancer information aimed at women with the disease. It provided many women with the information they needed to make their own decisions, and changed the balance of power between patient and physician.

In the early 1990's, scientific information on breast cancer was still difficult to find. The information available was inadequate and superficial and mainly produced by the government and established agencies (Batt, 1994). A variety of breast cancer activist groups were started in response to this lack of information. One of the most active groups, Breast Cancer Action, was founded by Elenore Pred, a veteran of 1960's civil rights and anti-war demonstrations (Batt, 1994).

In an effort to educate women with breast cancer about the most controversial practices in breast cancer care, Breast Cancer Action has posted multiple documents on their website. These documents discuss medical information from a critical standpoint. These articles are: access to health care, compassionate access to investigational therapies, breast cancer and the environment, genetic testing for breast cancer susceptibility, mammography and Tamoxifen (Breast Cancer Action, 2000).

The articles on Tamoxifen, mammography, genetic testing, and the environment review the current research that informs these interventions. These articles expose the limitations of the research, negative impacts of the treatments, and role of government and large corporations had in obtaining acceptance of these treatments. The articles about access to health care and access to investigational therapies discuss the American issues related to decreasing barriers so women with breast cancer can obtain quality health care (Breast Cancer Action, 2000).

Breast cancer activists have been concerned about the lack of critically appraised, accurate, and comprehensive information about breast cancer risk factors, prevention, screening, diagnoses, and treatment options. This type of information enables women to make informed decisions about their bodies, changing the balance of power between all-knowing physicians and un-knowing patients. Comprehensive information is produced by many breast cancer activists groups and individuals and can be easily obtained through the Internet, bookstores, and support groups. Physicians, health care organizations, and corporations are no longer the exclusive provider of information about women’s bodies and their cancer.
Safer, Less Invasive Treatments

Biopsies

In 1974, the time Rose Kushner had breast cancer, it was common for women to enter the operating room for a cancer biopsy and leave the room with her entire breast, chest wall muscles, and lymph nodes removed. When Happy Rockefeller was diagnosed with breast cancer she underwent general anaesthetic to have her biopsy taken. This tissue was then analyzed in the operating room and a decision to remove her breast was made by her surgeon and her husband while she lay unconscious on the operating room table (Batt, 1994).

Before having her biopsy and surgery Rose Kushner investigated the reliability of biopsies, comparing the effectiveness of frozen sections (done after the surgery) versus fresh sections (done during surgery) and determined that frozen sections were much more accurate (Kushner, 1982). After a long search Kushner found a surgeon that agreed to do a two step procedure – a biopsy, followed by mastectomy at a later date if needed. This provided Rose with the time she needed to consider her treatment alternatives.

Kushner went on to actively lobby the American government to make changes in the way breast cancer care was provided. She lectured, wrote and sat on committees to eliminate the practice of having biopsies and mastectomies occur as a singular surgical procedure. While Kushner was lobbying for these changes, American health insurers realized that it was cheaper for hospitals to perform a biopsy under local anaesthetic and then follow with a mastectomy, if needed, under general anaesthetic than to have all biopsies done under general anaesthetic. Eventually all hospitals adopted this two-step procedure as a cost-cutting measure, which also provided women with safer treatment (Kushner, 1982).

Breast Surgery

From 1900 to the 1970's medicine was governed by the non-science of anecdotalism. In the early 20th century, Halsted, a surgeon, proposed that breast cancer was a local disease that spread in a concentric pattern. He believed that it could be cured by extensive surgery. Halsted developed a surgical procedure that removed the entire breast, chest wall muscles and lymphatic system from the affected side of the body (Fisher, 1999). This surgery, called the Halsted procedure, was very aggressive and could only be done by a surgical specialist, enhancing the prestige of the surgeons that could perform this surgery (Batt, 1994). In the 1950’s the scientific process began, in which hypothesis generated from laboratory and clinical investigations could be tested by randomized clinical trials. This research began to dispute the hypothesis of breast cancer being a local disease that spread in a concentric pattern. By 1980 new research was starting to prove that even small tumors could spread cancer through the lymph nodes and blood (Fisher, 1999). In Europe the practice of breast conserving surgery, removal of the tumor and a small amount of surrounding tissue, followed by radiation therapy was proven to be as effective as the horribly disfiguring Halsted procedure (Batt, 1994). American surgeons
were unwilling to give up their practice, stating that breast cancer in European women was different than breast cancer in American women. The resistance of breast surgeons to stop the Halsted was mainly due to their unwillingness to give up their prestigious role, since almost any surgeon could do the simpler lumpectomy (Batt, 1994; Kushner, 1982). Power politics of surgeons prevented women with breast cancer from receiving safer, less disfiguring surgery. Eventually American surgeons gave up the Halsted procedure, but it was many years after Canadian and European surgeons had changed their practice (Batt, 1994).

**Tamoxifen Trial**

A more recent controversial practice that activists have been involved in writing, lecturing and lobbying against has been the Tamoxifen prevention trial. Tamoxifen is the world's leading breast cancer drug. It is prescribed to over 500,000 women in the United States, and annual sales of Tamoxifen totals $250 million. Tamoxifen has been used very successfully to prevent a recurrence of breast cancer for women with some types of breast cancer. There is now a research trial to evaluate its effectiveness to prevent breast cancer in high-risk women (Breast Cancer Action, 2000).

The Tamoxifen prevention study involves giving Tamoxifen to a large number of healthy women. Subjects of the trial were to be women at high risk, any women over 60, and any women over age 35 whose risks (such as family history and childbearing status) is equivalent to that of a 60 year old woman. Researchers expected the subjects to be mainly older women, but to date 43% are healthy young women, women who wanted to believe in the promise of Tamoxifen. Many scientists have objected to this study because of its inherent risks and because there is no data to support the use of Tamoxifen in premenopausal women (Breast Cancer Action, 2000).

Tamoxifen is a not a benign drug, it is a carcinogen, and it has been proven to cause endometrial cancer and has the potential to cause ovarian, liver and gastrointestinal cancer. In September 1995, the California division of the Environmental Protection Agency attempted to add Tamoxifen to its carcinogen list, which already had other chemotherapy agents on it. A powerful lobbying effort by Zeneca (the manufacturers of Tamoxifen) convinced the Governor of California to not add Tamoxifen to the list. The lobbyists believed that by having this drug on the list, women would unnecessarily stop taking the drug. Breast Cancer Action testified in support of having Tamoxifen on the list so full disclosure of the carcinogenic potentials of the drugs would be available to the public (Breast Cancer Action, 2000).

Tamoxifen has other indiscretions in its past. In 1994 it was revealed that the National Cancer Institute withheld information from women about their increased risk of fatal uterine cancer for women taking this drug. In 1992, a congressional hearing revealed that more than half of the informed consent documents for the prevention study failed to mention one or more of the major possible side effects of Tamoxifen (Batt, 1994).
It appears that many decisions about this trial have been based on politics and profit, not the best interest for women with cancer. If all women knew about the risks of Tamoxifen, how many would decide to not take the drug? How would this affect sales and scientists careers? Eight years after the beginning of the prevention trial, only 8,000 women have been enrolled in the study that is trying to recruit 16,000 women. Many sites have quietly stopped recruiting for this study.

Women with breast cancer have the right to safer, less invasive treatments. For many years physicians and large health care corporations have dictated what treatment a woman with breast cancer would receive. Often these treatments were not in the best interest of the women with cancer. Women with breast cancer need access to comprehensive information so that they can chose not to have overly aggressive treatments that do not have any better outcomes than the less invasive treatments.

**Environmental Links**

Breast cancer is one of several cancers that has had an increase in the incidence rate since the end of World War II, which heralded the increase in use of toxic chemicals. Studies have linked increased breast cancer rates with exposure to hazardous waste sites, chemical facilities, polyvinyl chloride, pesticides, synthetic estrogens and medical ionizing radiation. Even though evidence is mounting on the link between exposure to disease causing agents and breast cancer, public health educational pamphlets on breast cancer continue to focus on personal health habits as a way to reduce cancer risk. This focus on health habits frames breast cancer as a problem related to individual behavior, rather than as a problem of exposure to disease causing agents. In 2000 only 2.5% of American government funding on breast cancer research was earmarked for environmental exposure studies. Breast cancer activists want to redirect the “blame” for breast cancer from personal behaviors to environmental contamination by large corporations. Many breast activist groups have combined efforts with environmental groups to pressure governments to pass legislation to ban toxic substances and increase spending on environmental research (Boehmer, 2000).

**Environmental Exposure**

Environmental researchers are now able to link exposures to toxic substances to an increase in a woman’s risk of developing breast cancer. In one study it was identified that United States counties with hazardous waste sites were 6.5 times as likely to have increased breast cancer rates than other counties without hazardous waste sites. The Long Island Breast Cancer Study Project is continuing to study the link between breast cancer rate and proximity to chemical facilities. The more chemical plants in the vicinity, the higher the cancer risk is for women residing in those areas. In Cape Cod, where the breast cancer rate is 20% higher than the rest of Massachusetts, studies have been done to identify causality. Women of Cape Cod have the same ethnicity, screening practices, lifestyles and family histories as other women in Massachusetts, yet the rate of women
under 65 developing breast cancer is significantly higher. This study is now taking environmental samples of dust, soil and air, to determine if the cause is environmental (Stiengraber, 2000).

In Kentucky, areas with the highest breast cancer rates also had the highest use of the pesticide triazine, a weed killer used in cornfields. Triazine has been the most frequently used pesticide in the United States. Its is known to leach into the ground water and has been found in oranges, apples, meat, milk, poultry, and eggs. Triazine use in many parts of Europe has been heavily restricted due to links with breast and ovarian cancer (Stiengraber, 2000). When research on DES, another pesticide, demonstrated a strong link between its use and cancer, the company that produced it was able to hold back the publication of this study for six years (Batt, 1994).

**Occupational Exposure**

Research has been unable to identify links between occupational exposure and breast cancer, because for many years women were not subjects of these studies. Studies on polyvinyl chloride (PVC), a major component of garden hoses, lawn furniture, floor coverings, toys, food packaging and credit cards, have shown links to liver, lung and brain cancer. When a preliminary study on women and PVC’s was done, a link to breast cancer was also found. There has not yet been a comprehensive study on PVC and breast cancer. Peter Infante, the Director of the Heath Standards Program at the Occupational Safety and Health Administration, believes that the absence of women in occupational studies shows an indifference to the plight of female workers (Stiengraber, 2000).

**Pesticides**

Since the mid-1970’s studies have shown that pesticide levels in breast tumors are significantly higher than in healthy breast tissue. Studies have also shown that women with high levels of pesticides in their blood are more likely to develop breast cancer than women with low levels of pesticides in their blood (Stiengraber, 2000). In 1997 one large study showed that there was no link between blood levels of the pesticides PCB and DDT and risk of breast cancer. Some detractors used this one study to claim that all pesticides were safe. Researchers that have continued to question the safety of pesticides were referred to as engaging in “voodooism which faithfully treads the old and fearful pathways of a disease-fearing heart” by the 1997 editorial in the *Toronto Globe and Mail* (Stiengraber, 2000).

**Synthetic Estrogens**

Xenoestrogens, foreign chemical that act like estrogen, have also been implicated in breast cancer. Even though xenoestrogens are found in the body at much lower levels than naturally occurring estrogen, they have been shown to modify natural estrogen so that it initiates and promotes the growth of breast cancer (Stiengraber, 2000).
Radiation

Medical ionizing radiation (x-ray exposure) has been proven to cause breast cancer. Lifetime exposure and exposure to women under 20 seems to have the biggest impact on developing breast cancer. Women who underwent frequent fluoroscopies (real time x-rays) for tuberculosis, radiation therapy of enlarged thymus as a newborn and pediatric fluoroscopies of the heart have a substantially higher rate of breast cancer than the general public. There is no established dose limit for patients, yet there is a dose limit for technicians (Stiengraber, 2000). The 1997 Breast Cancer Etiology Working Group, hosted by the US Department of Health and Human Services, which reviewed breast cancer and medical ionizing radiation made the following consensus statement:

Ionizing radiation is an immediately preventable known cause of breast cancer and other cancers, and the breast is particularly susceptible to damage from ionizing radiation. While many of these sources (of radiation) cannot be modified at this time, the medical use of ionizing radiation can be identified as a universal problem that is modifiable. It has been estimated that a threefold reduction of dose from diagnostic radiology is technologically feasible. (Stiengraber, 2000).

More research is needed to investigate the links between environment and breast cancer. There also needs to be a move away from blaming women’s personal behavior for their breast cancer while large corporations are protected from queries about how environmental exposures, occupational exposures, pesticides, synthetic estrogens, and radiation environment may be possibly linked to breast cancer.

Breast Cancer as a Political Issue

Until the breast cancer activist movement of the 1990’s, breast cancer was framed as a personal tragedy, one that was kept silent except for the few celebrities that spoke about their experiences to the media. In 1980 Audre Lorde, a black lesbian poet, wrote about her experience with breast cancer and the need to break the silence:

Each of these women has a particular voice to be raised in what must become a female outcry against all preventable cancers, as well as against the secret fears that allows those cancers to flourish. May these words serve as encouragement for other women to speak and to act out of our experiences with cancer and with other threats of death, for silence has never brought us anything of worth (Lorde, 1980, p. 10).

Lorde (1980) also recognized that women have been socialized to respect fear more than their own need to be heard. She warned her readers that if they waited for the fear to disappear before they spoke, it would be too late. People with AIDS took inspiration from Lorde’s work and began to speak about their issues and demanded to be heard.
It is ironic that a woman writing about breast cancer has inspired AIDS activists, while breast cancer activists remained silent for ten more years.

In the 1990’s several breast cancer activists groups began to form. All were formed by women with cancer, and realized political action was needed (Boehmer, 2000). Breast Cancer Action, founded by Elenore Pred, a veteran of the civil rights movement, is one of the most active groups today. In the year 2000, one of the goals for Breast Cancer Action was to make breast cancer a national priority through education and advocacy, recognizing that breast cancer is more than a woman’s private trauma, it is a national public health emergency.

Activists see breast cancer as a political issue. Cancer fundraising, treatment and research is a multi-million dollar industry that creates and sustains powerful careers for many people. Members of corporations and physicians make decisions about breast cancer care and research, while women with breast cancer have no voice in these discussions. Breast cancer activists believe that women with breast cancer are paying the price for their silence. Women with breast cancer need to be at the table when discussions occur about what research and treatments will be funded.

Summary

In the radical functionalist perspective, physicians and large corporations dictate breast cancer care. This has created an environment where the needs of the elite have superseded those of women with cancer. Research and treatments have failed to have a significant impact on preventing breast cancer or reducing the mortality rate of breast cancer. Research has focused on developing aggressive invasive treatments, instead of prevention. The power and prestige of physicians has prevented women from learning about, and directing their cancer care.

Radical functionalists believe that how breast cancer care is provided must be changed. Research must focus on finding new, non-toxic cures for breast cancer. Treatments for women must be based on research, not past patterns of practice of physicians. Power politics of physicians, health care organizations, and pharmaceutical companies should not dictate treatments, like what happened with the Halsted procedure in the United States. Women with cancer must have access to information so that they are fully informed of their treatment options. Most importantly of all, research must focus on how to prevent breast cancer, so another generation of women does not need to experience the terrors of breast cancer.
CHAPTER SEVEN

RADICAL HUMANISM

Radical humanists believe reality is based on a person’s experience, that each of us has an unique way of understanding our world, and that people carry a culturally constructed “false consciousness”. The goal of radical humanism is to transcend limitations of existing social arrangements. Ideological superstructures (government, schools, corporations, the media, etc.) dominate human consciousness by telling people what they are and what they want out of life, thus preventing them from becoming what they could be. Radical humanists attempt to release these constraints. Change in society can only happen after individuals recognize the alienation and negative consciousness created by these superstructures. Only when people live beyond the control of the superstructures, can society change.

When looking at breast cancer through the radical humanist lens, it is apparent how superstructures create expectations of how women with breast cancer will behave. This chapter will explore the subjective experience of women with breast cancer, recognizing how society shapes this experience, as well as recognizing how some women have protested against these expectations. Feminist theory is used to provide the framework for this chapter since it is largely nested in radical humanism.

Three issues are explored; how physical appearance defines a woman, how women’s needs are secondary to others, and how breast cancer is a taboo subject for most women. These issues are examples of how women with breast cancer behave in response to the pressures of society. Radical humanism functions on two levels; conscientization of individuals and action to overthrow existing social arrangements. The authors of the materials used in this chapter are attempting to bring to the readers’ consciousness how society superstructures dictate behavior. Once women recognize how these superstructures mold their experience, they can then move to discarding these expectations and living genuinely. Action is illustrated throughout this chapter, such as the story of the women from the dragon boat team, Abreast in a Boat. These women, all diagnosed with breast cancer, have rejected society’s expectation that they remain silent about their disease. Other examples of women’s actions are described to illustrate how women who are aware of society’s attempt to control their behavior rebel against these controls in an effort to live their life free from the expectations of society’s superstructures.

Feminist Theory

Feminist theory postulates that women live in a subjective world where others define self. From infancy, females are socialized to know themselves through others and to develop their self-esteem in reflection of the dignity others give them. Personal sacrifice, selfless
devotion, sympathy, generosity and mutuality define a woman's role. The process of becoming female continuously stresses connectedness to others, because women know themselves not as independent individuals in a social matrix, but through their relations with others - family, friends and culture. Women also define themselves through their physical appearance, comparing themselves to the cultural definition of women, a thin and sylph-like female, an improbable ideal for most women. This cultural expectation of beauty is extremely restrictive. Many women pursue this narrow definition of beauty at the expense of larger goals and projects. This undermines their identity and confidence. Even when women make decisions, the role of others is significant. Women are socialized to be deeply influenced by concerns for and advice from family, friends and culture (Kasper, 1988).

In the breast cancer experience, women are expected to behave in a socially acceptable way. Three of these expectations are discussed in this chapter – the importance of physically perfect bodies, how women’s needs are secondary to family’s needs, and how breast cancer is still a taboo subject.

**Boobs, Boobs, Boobs**

Public images have been used to create concepts of what is real and normal. Images provide the framework through which social existence is represented and interpreted (Fosket, Karran and LaFia, 2000). More specifically, these images give information about social roles, self-image, expectations and fantasies. All visual media have the same ideology; continual repetition of visual images that in time become part of the shared experience. The media constantly bombards people with the images of slim, young, women’s bodies. These images tell people that a perfect woman’s body is of great importance. Women should be physically attractive, sexually inviting, and maternal, and breasts are a central aspect of this image (Ferguson, 2000). Breasts should be full and voluptuous and those that do not conform to this ideal are considered abnormal. In 1947 a Newsweek article wrote that women who had small breasts were likely to suffer from extreme “neuroses” or “psychological disturbances” as a result of their breast size (Ferguson, 2000, p. 71). Almost 40 years later, in 1983, the American Society for Plastics and Reconstructive Surgeons made a natural, normal condition of small breasts into a deviant condition that warranted medical intervention:

There is substantial and enlarging medical knowledge to the effect that these deformities [small breasts] are really a disease which results in the patient’s feelings of inadequacy, lack of self-confidence, distortion of body image, and a total lack of well-being due to a lack of perceived femininity (Ferguson, 2000, p. 71).

The media and the medical establishment have convinced many women that it is necessary to have full breasts. It is estimated that more than two million women in the United States and three million women worldwide have had breast implants (Ferguson,
Women are admired, valued and viewed as objects of beauty because they have breasts. Women’s social status is directly linked to their breasts (Kasper, 1988).

When a woman is diagnosed with breast cancer superstructures have convinced them that if their breasts are violated they will lose femininity and value as a woman. Social standards equate normal women’s roles and relationships with a physical body that consists of two breasts. A loss of a breast equals a loss of role, a violation of the core sense of self (Kasper, 1988). Women have to grapple with the meaning of living with only one breast. They have had lifelong messages that women are valued for their appearance and are largely defined by their breast (Rosenbaum and Roos, 2000). These women have to confront the conflict between the old familiar socially constructed meaning of what it means to be a female and their new unfamiliar personal experience of being a female with a breast removed.

Women are sometimes surprised at how significant the potential loss of their breast is. For many women breasts are synonymous with being female. A woman in Kasper’s study spoke about the importance of breasts when thinking about breast cancer. “You know it’s pretty important, more so than I even would allow myself to acknowledge” (Kasper, 1988, p. 244). Women in this study were concerned that they would be less desirable, less feminine, and less womanly with only one breast. They worried that others may respond negatively to them if they do not look “normal” (Kasper, 1988). When contemplating the impact a mastectomy will have on her life, Sarah, a 70 year old African American had this to say:

I am desperately afraid. And wondering how am I going to stand at the mirror and see myself in that shape. It really takes a lot from me. I’m just the kind of a type that likes everything perfect, so it’s going to make a big difference. I don’t feel very feminine anyway. And I always thought my breasts were the only part about me that really looked [feminine] anyway at all. I probably would feel not feminine at all without them. It’ll affect me, my femininity. I feel like it’s been damaged. (Rosenbaum and Roos, 2000, p. 166).

Following surgery Sarah talked about the impact the surgery had on her feelings about herself:

I don’t think for a 70 year old woman I looked so bad and I just think with your breasts gone, you can’t help feeling bad about it. I see people on TV dancing and all that stuff and bosoms. I notice them all the time now. Now that mine’s gone, I don’t feel like a “whole person.” And I feel like I’m always gonna be not exactly whole anymore. (Rosenbaum and Roos, 2000, p. 167).

Sarah had embraced the socially constructed model of women being defined by, and primarily for, their appearance, and that a woman’s appearance is largely composed by her breasts. The media, social interactions, and the medical world consistently link
breasts to femininity, sexuality, identity and self-worth. Surgical alteration or removal of a breast is viewed as significantly decreasing a woman’s femininity, sexuality and over all self-esteem. Sarah had feelings of less self-worth, loss of womanhood, and damage to her sense of herself as a whole person (Rosenbaum and Roos, 2000). Another woman rejected the dominant model of the meaning of breasts and replaced it with her own view of femininity and breasts. After her mastectomy Gloria spoke about the popular notion that mastectomy compromises one’s femininity:

It’s just that my femininity, my womanhood, and my sense of self are not embodied in my breasts. My femininity is my caring, my nurturing, my warmth ... It’s an emotional kind of thing. I mean somebody with small breasts, or very flat chested, is not less feminine because of that. And I have always felt strongly about that (Rosenbaum and Roos, 2000, p. 168).

For most women, reconstructive surgery is the norm after a mastectomy. The medical literature describes reconstructive surgery as a natural part of breast cancer treatment, and women who choose not to have the surgery are sometimes identified for medical and psychiatric follow up (Ferguson, 2000). Reconstructive surgery promises to make women “whole again”, to assist them to go back to the person they were before breast cancer, and to provide them with a replacement for what was lost. Society expects women to want and seek satisfaction with reconstructed breasts (Kasper, 1988).

In Kasper’s study, more than 50 percent of women who had breast reconstruction felt ambivalent about its role in their recovery. One woman described breast reconstruction and emotional well being as two separate entities:

I mean, I don’t see it just because now I have a reconstructed breast I’m whole again ... It’s something I have to work out for myself, cognitively, emotionally, instead of just looking in the mirror and seeing another breast there (Kasper, 1988, p. 290)

Radical humanists believe that after a mastectomy or breast altering surgery, women need to find ways to come to terms with the difference between the socially constructed view of femininity and their own experience of being a woman with imperfect breasts. These women need new models of what it means to be feminine, sexual and maternal. Women need to be valued as individuals, people who have important contributions to make to society, not just as bodies with breasts (Kasper and Ferguson, 2000).

Women’s Needs are Secondary to Family’s Needs

Society expects women to put their needs behind those of their family; therefore when it comes to breast cancer, women are in the uncomfortable position of behaving outside expected societal norms. Interestingly, this issue is rarely addressed explicitly in the literature. Several articles on minority women and breast cancer talk explicitly about the
role of family priorities and breast cancer care. This section discusses how a woman’s responsibility for her family shapes her behavior during her breast cancer crisis.

Prevention

Over the years, mammography screening use has increased for most groups of women, but older African-American women tend to underutilize it. A study by Tessaro, Eng and Smith (1994) explores reasons why many African-American women do not attend mammography clinics. Several reasons for poor attendance at screening clinics were related to women setting a low priority for their own health-related behaviors. These women rarely visited physicians, and only sought health care when they had specific problems. They did not visit physicians for prevention or early identification of health problems. Husbands and sons reported that these women “worry more about the welfare of others than themselves” (Tessaro et al, 1994, p. 290). A woman’s own “bumps, lumps, aches and pains” are tolerated as “nothing special” (Tessaro et al, 1994, p. 291). The women themselves described taking care of their family before themselves. One woman described this behavior as entrenched in the consciousness of these women:

I think the black women don’t realize herself she has a tendency to leave herself alone and worry about other people. So she doesn’t have a chance to examine her body and see what is really wrong with it (Tessaro et al, 1994, p. 291).

Society expects women to put their needs after the needs of their families, therefore their use of health care services to care for themselves are poorly utilized.

Treatment Decisions

When undergoing treatment for breast cancer many women still tend to relate the illness experience to the impact it has on their families. In studies with Korean (Im, 2000) and Chinese-American women (Facione, Giancarlo and Chan, 2000), both groups discussed the impact cancer had on their ability to care for their family. Im (2000) postulates that this concern for family may dictate what treatment decisions these women make.

In Kasper’s (1988) study of middle-class Caucasian American women with breast cancer, several women spoke about guilt they felt about putting their needs first. Women are socialized to make decisions about themselves in the context of the needs of others, and when breast cancer makes them put their needs first, this creates internal tension and conflict. One woman in the study described choosing a treatment plan in her own best interest as ‘egotistical’:

...being egotistical is not a nice thing. I was always brought up to thinking that being egotistical and self-centered was not favorable. That we ought to be considerate of other people. And the [other people] sometimes first and foremost. (Kasper, 1988, p. 365)
Another woman described how the cancer experience had changed the way she makes decisions for herself:

I suddenly gave myself permission to say no and to let myself come first, and that was a real breakthrough and I think that was what I learned was taking care of myself. And . . . not being selfish, I, you know gave up the notion that it was selfish, but that I was important and I came first. (Kasper, 1988, p. 356)

When a woman is diagnosed with breast cancer, she must put her needs ahead of the needs of her family, an uncomfortable position for many women. This change in priorities goes against the social expectations of a woman to make personal sacrifices, provide selfless devotion, and to be generous to others.

Breast Cancer is Taboo

Breast cancer has been defined by society as a private issue; women are encouraged to hide their experience of breast cancer with breast augmentation, prosthesis and a cheery smile when asked how they are coping. Illness should only be discussed with health care professionals and close family and friends. Audre Lorde wrote about her experience with breast cancer in 1980 breaking the silence. Today it appears that everyone is talking about breast cancer and it is no longer kept silent, but much of the discussion is by health care professionals and famous women. When women do speak out about their breast cancer, it is in direct conflict with societal expectations. This section will discuss how women hide their breast cancer through silence and prosthesis and augmentation surgery.

Silence about Breast Cancer

Most women do not talk openly about any kind of cancer. Cancer involving the breast is even more of a taboo. Society does not expect women to share intimate details about illnesses, and society also defines “coping well” with a disease as keeping emotions and thoughts to self and family members. Real women rarely talk about breast cancer, and if they do, it is mainly about people dying from it. In numerous studies, when women with breast cancer spoke about their experience, almost all spoke about their fear of dying from cancer. Breast cancer as death is a prevalent theme for almost all women in these studies (Utley, 1999; Tessaro et al, 1994).

Even thought women fear dying of breast cancer, they rarely share their concerns with others. If they do share their feelings about having breast cancer, others admonish them for “not coping well”. In Rosenbaum and Roos’ study one woman was very aware of the expectation of keeping her emotions blanketed to demonstrate to others she was coping well with her cancer. A colleague at work criticized her for talking about her cancer too much and not “getting over it” quickly enough. She rejected the predominant belief that women should be silent about their breast cancer to prove to others that they are coping.
I mean if I express my frustrations and I express my fears, does that mean then that you say to yourself, “Oh, God, this woman is out of control.” It’s not an indication to me [that I’m not coping], but I am fearful that it might be to someone else. I think the fact that I can express those concerns is an indication that I am coping, dealing (Rosenbaum and Roos, 2000, p. 174).

Society expects women to take on the traits of personal sacrifice, selfless devotion, sympathy and generosity. Women are expected to protect their families through personal acts of sacrifice. Often women stay silent about their breast cancer and do not discuss their true feelings about how difficult it is to have it and to go through the treatments in an effort to protect their families from the emotional distress of the disease. One young woman explains how her silence protects her family:

I’m not too able to talk to my family. They will ask me questions. My feeling is they want to hear the good side of the story. What do you call it? “The bright side”. And I’m encouraged to keep my chin up. And one of my family members thinks or acts like the whole thing is not really serious. They don’t want to feel [the things I’m feeling]. I think they are terrified of feeling it. And I’m wondering . . . what am I going to do about that. If I’m going to feel compelled to support them in their illusions, or if I’m going to feel like I want to talk to them about it. I feel like I have to protect them. Or help them protect themselves is really what it comes down to (Rosenbaum and Roos, 2000, p. 175-176)

For many women, breast cancer support groups have become safe havens to talk about their experiences, to be understood, and to learn from others. These settings remind women with breast cancer that they are not alone in going through the breast cancer experience (Rosenbaum and Roos, 2000). Unfortunately, when women only speak about their experience with other women with breast cancer, the silence of the disease is perpetuated.

Prosthesis and Breast Augmentation

Audre Lorde believed women with breast cancer need to raise their voices against preventable cancers. She viewed prosthesis as a path of silence and invisibility. Prosthesis and reconstruction were just another way of keeping women with breast cancer silent and separated from each other. This emphasis on the cosmetics of breast cancer reinforced society’s stereotype of women, that women are only what they look like, so this is the only aspect of women’s existence that needs to be addressed. (Lorde, 1980). Society expects women to wear a prosthesis, to keep the epidemic of breast cancer silent and hidden (Lorde, 1980).

Lorde’s ‘Cancer Journals’ (1980) details her experience of going without a prosthesis. Ten days after her mastectomy surgery she returned to her surgeon’s office, one of the top breast cancer surgeons in New York City, for a check-up. When she arrived she was scolded by the nurse for not wearing a prosthesis: “You will feel so much better with it.
on,” she said. “And besides, we really like you to wear something, at least when you come in. Otherwise it is bad for the morale of the office.” (Lorde, 1980, p. 59).

Lorde raged against this incident. She believed that women with breast cancer are warriors. Her scars are an honorable reminder that she was a casualty in the cosmic war against radiation, animal fate, air pollution, McDonald’s hamburgers, and Red dye No. 2.

I refuse to have my scars hidden or trivialized behind lambswool [prosthesis] or silicone gel. I refuse to be reduced in my own eyes or in the eyes of others from warrior to mere victim, simply because it might render me a fraction more acceptable or less dangerous to the still complacent, those who believe if you cover up a problem it ceases to exist. I refuse to hide my body simply because it might make a woman-phobic world more comfortable (Lorde, 1980, p. 60).

Jo Spence, an outspoken photographer, who also had breast cancer also viewed prosthesis and breast reconstruction as a way to silence women.

Women with breast cancer are pressured by society to wear prosthesis, just as political and social injustices are covered up, so are injuries, deformities, and amputations (except honourable vets). Individuals are therefore isolated and are unable to recognize and share experiences with other survivors... conceals high incidence of injury (Spence, 1995, p. 62).

Prostheses create a silence about breast cancer. Women who cover up their mastectomies with prosthesis make their cancer invisible to society and to each other. Silence and invisibility goes hand in hand with powerlessness. By being silent, society does not have to recognize the epidemic of breast cancer and find ways of dealing with this disease. Women with breast cancer need to find ways to talk about their experience in the wider context. The problem with support groups is that women with breast cancer only talk to other women with breast cancer. The problem with breast reconstruction and prosthesis is that it hides a woman’s breast cancer from other women with breast cancer and from society.

In Vancouver there is a group of women with breast cancer who speak out loudly about breast cancer, they are the members of the dragon boat team, “Abreast in a Boat”. These women have taken the discussion of breast cancer out of the private domain and put it into the social realm. Over 100,000 people attend the annual Vancouver Dragon Boat Festival. These women, all women living with breast cancer, wear bright fuschia T-shirts that proclaim they are women with breast cancer. Originally these women began dragon boating as part of a research program on the safety of exercise post-mastectomy, but now these women have started a social commentary on breast cancer with the creation of teams throughout Canada, United States and New Zealand (Abreast in a Boat, 2000).

These women give voice to breast cancer. Over 100 women walk through the dragon boat site on race weekend in their bright pink shirts; it is impossible to ignore them. It
breaks the silence of breast cancer, it tells everyone that there are many women living with breast cancer and that they are not going to be silent anymore.

Summary

From a radical humanist perspective, society expects women to highly value their appearance, to put their needs behind the needs of others and to stay silent about their breast cancer experience. For many women these expectations conflict with their feelings and experiences of breast cancer. Societal expectations have effectively silenced most women with breast cancer; only a few celebrities have spoken about their cancer experience. Until more women speak out about their breast cancer experience, challenging the societal expectations of how women with breast cancer should act, women will continue to feel the conflict between society's expectations of their response to breast cancer and their own personal experience of the disease. When women talk about their breast cancer experience society's control of their experience erodes, and allows them to start the journey of allowing women to be free to experience their life genuinely, not to have their experience dictated by ideological superstructures.
CHAPTER EIGHT

FOUR PERSPECTIVES ON BREAST CANCER

When I began this study I was looking for a way to create some alignment between my academic and work lives. I had spent the past three years attending lectures and discussion groups at the university, talking about educational concepts, theories, and practices. I had been exposed to different viewpoints and assumptions about education and the world; many of these views were foreign to me. I remember one of my first classes in the Adult Education graduate program. A very intense Ph.D. candidate kept saying “that is not my view of the world” when we discussed various educational issues. I kept thinking, “what in the world is this woman talking about? – Of course that is the way it is, I’ve seen it and read it”. Throughout my studies I kept bumping into this kind of behavior, usually from those irritating Ph.D. students, who seemed wise, but often incomprehensible.

During this time I was working as an educator at a medium-sized hospital. My job was to teach nurses any topic I was interested in, since they seemed to want education of any kind. I spent time teaching about new equipment, procedures, and advances in medical technology. All of these classes were about the hard facts of medicine. There seemed to be a huge disparity in what I was learning at school and what I was doing in my job. To make matters worse, I got promoted to a position where my main responsibility was to introduce “evidence-based care” to the staff of the hospital. My role was to support nurses, physicians and other health care providers in changing their practice to align with what the randomized double blind studies were recommending.

My life was a dichotomy; functionalism reigned unchallenged in the hospital, while at the university it was viewed as only one of the many perspectives we would discuss. School was the place to explore ideas outside the mainstream, to challenge ideas we had relied on since we were children. I learnt fairly quickly to enjoy this alter-existence, I even became comfortable speaking and writing from these new viewpoints. Work became more and more uncomfortable; I needed a way to combine these worlds.

When it came time to begin work on my thesis I looked for a way of bringing these different perspectives together, to make some sense of how there could be different ways of looking at the same phenomenon. I needed a tool that could help me recognize a variety of different perspectives on health care issues and understand the similarities and differences between them. I believed that by seeing a health care issue from a variety of perspectives I would develop a more complex understanding of the phenomena. If this tool worked for me it may also work for other health care workers. In today’s climate where it is common for teams of health care professionals to come together to talk about health care issues, we desperately need tools to help us understand complex issues. I wondered if the four world-view model could do this. It had been used to describe educational theories, HIV education, fishing vessel accident prevention, environmental
education, and participation in international rural development projects, but could it be used to explain health care issues?

Using the Four World-View Model

I was introduced to the four world-view model (Burrell and Morgan, 1979; Paulston, 1996) several times in the first years at school. At the beginning I found it confusing, not understanding what each of the perspectives represented. As I learnt more educational theories I began to understand how this model pulled different theories together. It became a roadmap for me; graphically displaying how my work sits in one part of the model, while school hops around the other perspectives.

I began to see how different assumptions and perspectives drive people’s viewpoints, discussions, and practice. I started mapping co-workers onto this model; the surgeon I worked closely with sat in the functionalist perspective; the woman from health promotion wandered about the radical humanist section; my manager dipped between the functionalist and the radical functionalist perspective, believing that all issues could be solved if we just changed the structures of the health care system; and another woman I worked with always considered the “personal” issues related to any problem, and saw the world from a humanist perspective. It became easy to see how different people viewed the same issue from different perspectives.

Now that I had begun to look at how people viewed phenomena from different perspectives, I was interested in finding out if the four world-view model could be used to investigate a health care issue. I wanted to look in depth at a health care issue to determine if this model would bring forward new insights, and if all of the viewpoints could be captured by the four world-views. I decided breast cancer would be a good health care issue to pursue. My interest in breast cancer was coming from several levels. Personally I was interested in breast cancer since my mother had been treated for it five years ago, and I was now deemed high risk for developing breast cancer later in my life. During this time I had also witnessed the growing movement of women with breast cancer participating in dragon boat racing, and was impressed by how these women were making this disease so visible in the Vancouver sporting community. I felt that breast cancer was a complex disease that has many different meanings, so it would be a rich subject to investigate through this model.

Reimagining Breast Cancer through the Four World-View Model

By using the four world-view model to describe various perspectives of breast cancer, a broader discourse has been uncovered. This new discourse reminds us that there is no longer a universal explanation for phenomena. Multiple viewpoints must be recognized. No longer can breast cancer be defined solely by its biological components. The personal story of breast cancer, as well as society’s influence on how breast cancer is treated, what
is researched, and how women experience it must also be recognized. The four world-view model has exposed the complexity of the discourse related to breast cancer.

For many years breast cancer was only defined from a functionalist perspective. Biology defined breast cancer. Research identified various aspects of breast cancer; how cells multiply and grow, what treatments best halt the spread of cancer, and what treatments do not affect the growth and recurrence of breast cancer. When a breast lump is found women undergo multiple tests to determine the characteristics of the cancer. Physicians determine the best treatment protocol based on the properties of the tumor. Women then undergo surgery, radiation and or chemotherapy. This perspective is widely understood by both health care providers and members of the public. This study has identified three other perspectives of breast cancer; humanist, radical functionalist, and radical humanist.

The humanist perspective explores the personal stories of breast cancer. These stories can be found in qualitative research as well as in the lay press. Breast cancer has been described in many ways, sometimes as enemy, challenge and opportunity for transformation. When women speak about their cancer journey, the fear of dying, disfigurement, recurrence and loss of their past life frequently weighs heavily in the story. Other women have described their experience with cancer as a challenge, a hurdle to get over, just like so many other obstacles they have already experienced in their lives. Some women have experienced cancer as an opportunity for transformation, it provided them with an opportunity for positive personal growth. Each way of experiencing breast cancer needs to be recognized and honored for its truthfulness and legitimacy. These stories can no loner be silenced by the hegemony of the functional perspective of disease.

The four world-view model also provides space for perspectives regarding the role that society has taken in shaping the phenomenon of breast cancer. Both the radical functionalist and radical humanist perspective illustrate how society has influenced our understanding of breast cancer.

According to the radical functionalist perspective, large corporations and physicians, the elitist members of society, have been responsible for determining how breast cancer is researched and treated. These powerful groups controlled material resources and information, ensuring their needs for prestige and profits are met, with little regard for the needs of women with the disease.

Within the radical functionalist perspective women with breast cancer have had little influence in determining the research on breast cancer. Even though these women want answers about "why" they got breast cancer and if their daughters will suffer the same fate, almost all research money has been spent on pharmaceutical research. Research boards that determine what research projects will be funded are made up almost exclusively of physicians and research scientists. Less than 3% of American research funding on breast cancer is spent on environmental exposure studies (Boehmer, 2000). There have been preliminary studies that have shown potential links between environmental contaminants and breast cancer; yet this research continues to get very
little funding. In the past when studies were published that found environmental links to breast cancer, large powerful corporations attempted to keep the studies silenced. Corporations were protected at the price of women’s health.

Women’s lack of societal power has had a significant effect on the treatment patterns for this disease. Typically the physician determines the course of breast cancer treatment. Until the 1980’s most physicians recommended the disfiguring Halsted surgical procedure. Tens of thousands of women were mutilated by this procedure, a procedure that held very little promise for cure. For many years information regarding the success rate of this procedure was kept from women. The Halsted procedure was continued in the United States for years after European studies had shown its poor efficacy, ensuring continued prestige and wealth for the surgeons that performed these difficult surgeries. More recently, a prevention drug study of hormonal treatment kept information from the women enrolled in the study. Most women in these studies were never told of these potentially serious complications. Eventually the pharmaceutical companies were legislated to provide full disclosure of risk to women considering to sign up for this study. Important information was kept from women regarding the treatment of their disease. With this lack of information, women were unable to make informed decisions about their own bodies, depending on their physicians to make the best decisions for them. In some situations, physicians did not select treatments in the best interests of these women. Often decisions were made to continue the power and profitability of physicians and corporations, with women’s needs secondary.

The radical humanist perspective also illustrates ways social structures and privileged elites have influenced breast cancer. Society has blamed and shamed women into silence. Women have been convinced that it is necessary to hide breast cancer behind prosthesis and augmentation surgery to ensure their desirability and value. By staying silent about breast cancer, women fulfilled their role as mother and partner, putting their needs behind the needs of their family. Breast cancer continues to be a taboo subject; women hide their disfigurement and usually do not speak about the pain of their disease. This has created a silence. This silence has ensured that breast cancer is viewed as a personal tragedy, only spoken about in family circles, instead of as a preventable health care crises.

By looking at breast cancer through the four lenses of the world-view model, a broader discourse of breast cancer unfolds. Breast cancer is no longer just a biological issue that is treated with surgery, radiation and chemotherapy. It is a personal tragedy for the women with the disease, changing their lives forever. It is also a social phenomenon where society has influenced its treatment, research and how the women who have it experience it. If truth is sought, which can be defined as absence of concealment, it is necessary to make the invisible visible and not to reject particular ways of knowing. By using the four world-view model to describe the different perspectives of breast cancer new and diverse ways of seeing breast cancer are uncovered.
Implications for Health Care Teams

The four world-view model can be used to identify and compare multiple ways of viewing a phenomenon. The breast cancer program team, introduced in chapter one, could have used this model to assist in understanding the issue of breast cancer. In this team, a variety of people were trying to determine a community program to deal with breast cancer. Each member of the team had a different idea on how to spend the funds. The team made no progress in determining a plan of action—everyone was interested in working on different projects and spent their time convincing others what was the best way to spend the money. The four world-view model could have been used as a tool to facilitate the team in understanding the different viewpoints of the various members of the team.

Different points made by members of the group illustrate different perspectives. Physicians saw breast cancer from a functionalist perspective. They believed more high-tech equipment and technical staff was needed to screen more women, thus preventing cases of advanced cancer. Dietitians saw breast cancer from a radical functionalist perspective, viewing the role that fast food corporations have had in determining teenager’s diets. By providing much needed funding to high schools, large corporations, such as McDonald’s, Burger King, and Coca Cola have been invited into school cafeterias. This eroded work done by high school dietitians regarding promotion of a nutritious, healthy, diet, one the best resisters to disease. Community nurses wanted funding for a self-help group for women with breast cancer. This would provide these women with an opportunity to come together to talk about their illness, as well as possibly work together with the community open up dialogue about breast cancer. This program could take on either a humanist or radical humanist perspective depending on the work women with breast cancer chose to do.

These viewpoints could have been mapped onto the four world-view model, creating a graphical representation of the various ways of understanding breast cancer. This mapping of perspectives could provide an opportunity for team members to identify and compare differences and similarities between their viewpoints. This openness may lead to a more comprehensive and complex understanding of breast cancer, which may provide opportunities for creative program planning. Exposing different viewpoints does not necessarily lead to better understanding; but without this exposure, there is no opportunity for creating a more inclusive definition of breast cancer.

The four world-view model creates space for multiple viewpoints; team members need to be sensitive and respect different viewpoints. This model does not guarantee better understanding between team members, but it provides a tool for those willing to listen and learn from others. Often in health care planning there is no room for alternative viewpoints. The powerful functionalist viewpoint goes forward unchallenged. The four world-view model can provide space for alternative viewpoints.
Implications for Education

Continuing Education for Health Care Professionals

As the research that drives health care continues to expand exponentially, health care professionals are expected to continue their studies throughout their careers. Often conferences are organized to share the “latest advances in health care science”. These conferences are usually held in gigantic conference centers, with distinguished speakers lecturing on the newest advances in the field. In the past these conferences have been mainly attended by physicians, but now are usually multi-disciplinary with nurses, social workers, physiotherapists and other health care professionals presenting and attending.

Many of these conferences are now inviting the public to attend in response to their requests to learn more about their diseases. This inclusion of the public has made conference planners re-look at the structure and format of these sessions. In March 2001, a conference entitled “Women and Cancer: Myths and Realities” was sponsored by the Interprofessional Continuing Education Department of University of British Columbia and supported by the B.C. Cancer Agency, B.C. Women’s hospital and the Canadian Breast Cancer Foundation. This conference had an agenda that included the latest pharmacological breakthroughs, clinical implications of genetic testing, advances in radiotherapy and reconstructive surgery as well as holistic treatments and patients sharing their “journey”. This has been described as a “truly inclusive conference” which represents a “groundbreaking attempt to bring all cancer groups onto the same page” (Brook, 2001).

When viewing this conference through the four world-view model it becomes apparent that this may not represent all of the perspectives on cancer. Historically the functionalist viewpoint has always been well represented at these types of conferences and continues to be through the presentations on pharmacological breakthroughs, clinical implications of genetic testing, advances in radiotherapy and surgery. The new addition to this venue is the humanist perspective, which was represented by the narratives of women with breast cancer. It appears that the radical functionalist and radical humanist perspective may still be missing from this “inclusive” conference. The website for this conference did not outline any presentations that reflect the viewpoints of the radical functionalist or radical humanist perspectives.

If a conference planner wanted to create a truly “inclusive” conference, the four world-view model could be used to create a framework for the program of speakers. This would ensure that multiple viewpoints would be heard.

Several years ago I was part of a small committee that planned a one day education session on AIDS treatment. We used the four world-view model as a framework and invited speakers that represented each of the perspectives. There were the traditional functionalist speakers, speaking on the advances of pharmacology, there were humanists speaking of the journey for themselves as well as their family members and there was a
radical functionalist/humanist who spoke about the experience of being a woman with AIDS. Her story included the absence of research on women with AIDS, the inefficient diagnosing of women with AIDS, the lack of drug trials available for women, the exorbitant costs of drugs, the logistical difficulty of completing a course of treatment, the need for childcare support when women were ill, and the blame and shame women experienced from health care workers as well as the public. This story was in stark contrast to the presentation on “pharmacological advances” as well as the personal stories that spoke about the symptoms and treatments of AIDS. This woman described a side of AIDS that is rarely spoken about. Most health care workers who attended this session were shocked to hear about these issues. These issues had remained hidden behind the hype of “medical breakthroughs”. By balancing the perspectives presented at the conference, a broader, more comprehensive understanding of AIDS was shared.

Education for Health Care Students

A common assignment for health care students is to research a “disease” and share what has been learned with their fellow students. Research tools have been taught to students to assist them to critique the available literature, but other tools are needed to assist students to expand their definitions of diseases.

In discussion with a nursing instructor from The University of Northern British Columbia, the usefulness of the four world-view model for guiding student learning was explored. After a quick explanation of the model, and how it has been used to describe breast cancer, the instructor was easily able to apply it to her field of expertise, pediatrics. We looked at Fetal Alcohol Syndrome through the four lenses of the model. She quickly gave examples to illustrate each perspective. The four world-view model was seen by her to be a useful tool to expand the definition of Fetal Alcohol Syndrome. She is now planning on using this model with her third year nursing students to open up discussion on the variety of perspectives that can be used to define a disease.

The four world-view model has the potential to be used in health care students’ studies to expand the discourse on disease. Diseases are often defined by their biological components, with the personal and social aspects being neglected. By using the four world-view model, space is made to explore a variety of perspectives that influence the understanding of the disease.

Education for the Public

Pamphlets and books on breast cancer are plentiful. This literature attempts to explain to the lay person what is breast cancer, how to prevent it, and what the treatments encompass. The focus of these pamphlets and books are to explain the functional, biological perspective of breast cancer. Often there is some information regarding the experience of the women with breast cancer, recognizing the difficult personal crisis this can be. This type of literature usually only focuses on the functional perspective, with a token recognition of the humanist perspective. If the four world-view model was used as
the framework for this literature, a more comprehensive, inclusive description of breast cancer would be provided.

The role of society in breast cancer research, treatment and experience could be included in public information, thus providing a broader description of the disease. Women with breast cancer could learn about the preliminary links between environmental toxins and breast cancer and could modify their lives and the lives of their daughters to potentially protect themselves from breast cancer. Women could also read about the role large corporations have had in dictating what research is funded and what treatment regimes are pursued. This would allow women to enter more meaningful discussions with their physicians when talking about the success rate of different treatments. Also viewpoints on how society dictates how women respond to a breast cancer diagnosis may provide women with insights on how actions such as prosthesis and breast surgery reconstruction silence the breast cancer epidemic, preventing it from gaining the recognition of the health care crises that it is.

This type of information may not change the way women respond to breast cancer, but it will provide women with more knowledge regarding the choices they make about the disease. The four world-view model is a tool to open up the discussion on phenomena, to allow space for alternative viewpoints and to end the silence of the minority groups. What people do with this knowledge will be up to them, but as educators and information providers, we need to find better tools to explain complex phenomena so people have opportunities to make informed viewpoints and decisions.

**Implications for the Four World-View Model**

The four world-view model does function as a tool to broaden the discourse of breast cancer. This model has previously been used to map educational theories, HIV education, fishing vessel accident prevention, environmental education and participation in international rural development. This is the first time this model has been known to be used to define a health care phenomenon. By using this model, space has been provided for a variety of perspectives on breast cancer. The resulting definition of breast cancer is complex and broad, bringing multiple viewpoints into it. Minority viewpoints have found space alongside the overpowering functionalist perspective. In discussion with other health care colleagues, its utility to describe other health care phenomena seems possible.

The four world-view model provides space for different perspectives, which can be woven into program planning, continuing education for health care professionals, student education and public education. Over the past year I have explained this model to a variety of health care professional colleagues. Once the two dimensions, subjective and objective and challenge and reinforce, are explained and plotted on a diagram, discussion can then occur about how these dimensions line up in health care. As my proficiency in explaining this model has improved, I have been involved in a variety of interesting
conversations about the utility of this model. Several colleagues were immediately able to grasp the applicability of it to education, while others were able to use it to describe “radical fringes” of health care that previously did not exist in relation to other viewpoints. I have been amazed at the insights and enthusiasm that has come forward in discussion of this model. I have been asked to speak at a small health care research conference, introducing the model as a framework for the conference. I have also had a variety of discussions about how this could be used in the mental health field, in an effort to be more inclusive and comprehensive. Many health care colleagues have told me that this model could be a useful framework for planning and educational programs.

Strengths of the Study

This study has a number of strengths. The literature used in the data collection came from a variety of sources; medicine, nursing, sociology, environmental studies as well as poetry, photojournalism and breast cancer activist web sites. To accurately reflect the four perspectives, literature was collected from a diversity of resources.

The need to determine a broad understanding of breast cancer was inclusive in nature. Often studies become more and more narrow, eliminating viewpoints that do not reinforce the concise question under study. This study attempted to broaden understanding, to make space for a variety of views that are often silenced by the health care profession.

Finally, this study has practical applications. It not only broadened the understanding of breast cancer, but also makes numerous recommendations on how it could be implemented in the “real world”. Every year thousands of women are diagnosed and die from breast cancer. This study attempts to expand the understanding of this disease, as well as recommend ways to make program planning and training more reflective of the complexity of the disease.

Limitations of the Study

Due to the design of this study, there were several limitations. Even though this study was based on the work by Paulston, it differs in several significant ways from Paulston’s study. Paulston used the model to map educational theories. This study used the model to describe different perspectives of breast cancer, not to review models that inform these understandings.

Findings from the study were not “mapped” onto the model to demonstrate their relationships to the four perspectives and to each other. The findings of the study were simply a description of four different perspectives on breast cancer, created through the literature. The purpose of describing the four different perspectives was to create a broader discourse than was traditionally recognized.
Samples of literature were used to create the descriptions of the perspectives. Samples selected were ones that clearly depicted one viewpoint, even though many articles found were comprised of a mixture of perspectives. By only selecting "pure" samples, it was possible to create four distinct description of breast cancer, one to reflect each perspective. If literature that reflected a mixture of perspectives were used, mapping would have been necessary to depict the overlap of viewpoints.

The descriptions of the four viewpoints were created from samples of the literature. They were not created by a comprehensive review of all literature present on breast cancer. More literature may have uncovered additional examples of issues; but it seems unlikely that these additional issues would have changed the four perspectives identified in the study.

Summary

The four-world view model was able to broaden the discourse of breast cancer. This model is an effective tool for expanding the understanding of phenomenon. It allows space for multiple viewpoints, making the invisible visible. In the post-modern world we need tools that assist us in seeing past the dominant viewpoint, allowing us to recognize minority views in an effort to create a more comprehensive and complex understanding. Typically health care professionals define disease by its biological properties, rarely recognizing the personal and societal aspect of disease. The four world-view model provides space for the personal stories as well as recognizing society’s role in disease. When I first began this study, I was unsure how a sociological model could describe a health care phenomenon. Like my colleagues, I had very little recognition of the role society has in disease. This study has shown the significant role society plays in how we construe and manage disease.

The four world-view model provides us with an opportunity to look at the issue from a variety of perspectives, seeing what was not visible before. At the beginning of this study I heard an interesting comment – from a hospital chaplain speaking about faith – “I can’t believe what I don’t see”. This statement has been a guiding light for me. Until we can open up space for different ideas and viewpoints, and make the invisible visible, we will not be able to understand phenomenon in a rich and deep way. The four world-view model provides that light and space, allowing us to enhance our understanding of significant issues.
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